

THE IMPACT OF SUMMER BREAK FROM SCHOOL ON CHILDREN WITH SEVERE
AUTISM AND THEIR PARENTS:

An Interdisciplinary Study

by

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Abstract

The purpose of this research was to investigate the effect of summer break on the academic, social, life, communication, and behaviour skills of elementary children with severe autism and to assess the recoupment of skills in the fall. Regression and recoupment were measured by testing academic Individual Education Plan (IEP) goals based on the Assessment of Basic Language and Learning Skills (ABLLS) and the Vineland Adaptive Behaviour Scale (VABS) at four time points to assess a baseline in school, the effect of summer, and the effect of returning to school, and with parent interviews. The research found that students with severe autism regressed in academic skills over the summer break, but recouped those skills within four weeks of returning to school in the fall. The other areas, rated using the VABS, did not change either during the school year baseline or over the summer break, but according to parent interviews social skills decreased and maladaptive behaviours increased.

The secondary purpose of this research was to study the impact of summer break on the stress of parents of children with severe autism and to gain a qualitative understanding of the impact of summer break. Stress was assessed using the Parent Stress Index (PSI) during the school year and then again during the summer and with parent interviews. The research showed that there were increases in parent stress during the summer break. Parents reported in interviews that summer break also had an overall negative impact on child emotions, parent relief, the child's break from the parents, and the structure of the family day, and that all of these, in addition to changes to skills and behaviours, contributed to parent stress. Summer break also had a negative impact on finances and siblings and some positive effects according to interviews.

Parents saw their children's disability as primarily social, requiring interventions and supports from society, while also acknowledging impairment effects. Parents suggested quality, structured, funded relief programs and workers as a solution to the negative impacts of summer break.

Keywords: severe autism, autism education, summer break, regression, parent stress

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Introduction

Autism is defined in the Diagnostic and Statistical Manual (DSM-V) (American Psychiatric Association, 2013) by impairments in social interaction and communication and stereotypic behaviour. (See Appendix A for a list of acronyms.) Children with autism may also have difficulties in many other areas, such as behaviours, motor skills, self-care skills (National Research Council, 2001), and rate of educational development (Ministry of Education, 2001). Schools in Ontario provide programs in these areas of difficulty based on the student's Individual Education Plan (IEP). The expectations in the IEP can be based on modified goals from other grade levels, or alternative goals (Ministry of Education, 2000). Schools are required to utilize the evidence-based teaching method of applied behaviour analysis with students with autism according to PPM140 (Ministry of Education, 2007).

The evidence suggests that summer break has a negative effect on the achievement of specific groups of students, such as low socio-economic class students (Cooper et al., 1996), and students with special education needs (Shaw, 1982). The existing evidence also suggests that students with special education needs recoup skills lost over the summer more slowly than students in the regular program when returning to school in the fall (Menousek, 1983). The purpose of this research was to investigate the effect of summer break on the academic, social, life, communication, and behaviour skills of elementary children with severe autism. This research also assessed the recoupment of skills. If students with autism regress over the summer break, and recoupment requires a significant amount of time in the fall, then the learning of students with autism is greatly negatively affected, and this has implications for educational policy.

The research on the stress of parents of children with autism suggests that they experience more stress than other parents (Pisula, 2003). Child variables that influence the level of stress of parents of children with autism include the child's autism symptom severity (Ingersoll & Hambrick, 2011), adaptive skills (Hall & Graff, 2011), and problem behaviours (Phetrasuwan & Miles, 2009). Also, when there is support in the form of care for the person with autism, parent stress is reduced (Ekas, Lickenbrock, & Whitman, 2010). A secondary purpose of this research was to investigate the impact of summer break on the stress of parents of children with severe autism and to gain a qualitative understanding of the impact on parents. Parents of children with

autism already experience a great deal of stress, and if summer break, through dealing with child regression in areas that influence parent stress or lacking care support for the child with autism, increased this stress, then families of children with severe autism may require more assistance over this break to reduce their levels of stress.

This literature review begins with a brief review of autism and autism education. The literature on the effects of summer break from school on student achievement, including the achievement of students with special needs, is reviewed, including recoupment research. The research on the impact of a child with autism on parents is then reviewed. This leads to the rationale for the current investigation. In the following sections, the research method is explained and the results are analysed and discussed.

1.1 Autism and Autism Education

An understanding of autism and autism education, including applied behaviour analysis (ABA), is critical to understanding the population being studied and the nature of the school break.

The National Research Council (2001) introduces autism as a spectrum disorder that

“has life-long effects on how children learn to be social beings, to take care of themselves, and to participate in the community... the manifestations of autism vary considerably across children and within an individual child over time. There is no single behaviour that is always typical of autism and no behaviour that would automatically exclude an individual child from a diagnosis of autism, even though there are strong and consistent commonalities, especially in social deficits” (p. 11).

At the time this research began, autism was defined and diagnosed in the participants by the Diagnostic and Statistical Manual – IV (DSM-IV) as “autistic disorder”, one of five disorders listed under the heading Pervasive Developmental Disorders (PDD) (APA, 1994). That category also included Rett's disorder, childhood degenerative disorder, Asperger's disorder, and pervasive developmental disorders-not otherwise specified (PDD-NOS). The American Psychological Association's (APA) DSM-V, published in May 2013, combines childhood degenerative disorder, Asperger's disorder, pervasive developmental disorders-not otherwise specified, and autistic

disorder into autism spectrum disorder (ASD) (APA, 2013). The DSM-V then gives three levels of severity for ASD, from requiring support to requiring very substantial support in social communication and restricted interests and repetitive behaviours.

Jensen and Spannagel (2011) claim that a single descriptor of functioning does not capture the complexity of the spectrum of autism. They use a two dimensional graph to create a chart with levels of autism symptoms (autism severity) on the x axis and level of cognitive impairment (deficit) on the y axis. Asperger Syndrome is placed in the top right hand corner with minimal symptoms and average to high IQ, and classic autism is in the bottom left corner with severe symptoms and severe deficit. Other students fit somewhere in this two dimensional chart, as opposed to a one-dimensional spectrum. It is students with high autism severity that are of interest in this study.

Autism, or “autistic disorder”, in the DSM-IV required the child to have impairments in social interaction such as impairment in the use of multiple non-verbal behaviours such as eye contact, facial expression, body postures, and gestures used in social interaction; impairment in communication such as a delay in, or lack of, the development of oral language; and stereotypic behaviour such as a preoccupation with an interest that is abnormal (APA, 1994). Delays in social interaction, social language, or symbolic or imaginative play must be present before the age of three years. The DSM-V groups social communication and social interaction across multiple contexts together into one section, and keeps the sections on restricted and repetitive patterns of behaviour, interests, or activities and the symptoms' presence at a young age (APA, 2013). Autism is diagnosed by a doctor or psychologist who will typically use a diagnostic test of autism like the Autism Diagnostic Observation Schedule (ADOS) or the Childhood Autism Rating Scale (CARS), as well as observation and history, which are based on the current definition of autism in the Diagnostic and Statistical Manual for Mental Disorders.

The Ontario Ministry of Education (2001) has its own labelling system for IEPs, called identification. Students who have been diagnosed with autism are then identified in the school as having a “communication exceptionality”, which is defined as a severe learning disorder with deficits in the rate of educational development, the ability to relate to the environment, motor skills, perception, speech, and language, and the representational symbolic behaviour that

precedes language. A diagnosis of autism by a doctor or psychologist based on the DSM is required before an identification of communication exceptionality can be given by a school team.

Children with autism also commonly experience hyper- and hypo- sensitivities to multiple senses (Davidson, 2010), seizures, behaviour difficulties, motor difficulties, self-care difficulties (National Research Council, 2001), and atypical physical, psychological, and perceptual difficulties (Bumiller, 2008).

1.1.1 The Individual Education Plan

Like all students in the education system, students with autism are expected to progress through a curriculum, although that curriculum will often include modified goals using curriculum expectations from different grades or alternative goals to the provincial curriculum that are designed for the particular student's needs (such as goals below the kindergarten curriculum or in areas that are not in the provincial curriculum, such as self-help skills). Students identified with a communication exceptionality like autism in Ontario require an individual education plan (IEP), which includes the modified or alternative goals, or “learning expectations” as well as other program or curriculum planning information such as student strengths and needs, student level of achievement, special education strategies, and assessment methods (Ministry of Education, 2000). Students with autism may have goals that other students usually learn on their own or typically acquire as they develop without formal instruction, such as making eye contact when listening, or responding appropriately to other stimuli.

Many school boards use a published curriculum designed specifically for students with autism, such as the Assessment of Basic Language and Learning Skills (ABLLS). The ABLLS, by Partington (2006) is divided into four skills assessment areas: basic learner skills, academic skills, self-help skills, and motor skills. These areas are further divided into 25 smaller skills areas. Each of the 25 skills areas include a variety of tasks that are scored out of 1, 2, or 4 with criteria for each level. The ABLLS is used for both program planning in the Individual Education Plan and assessment for the report cards.

1.1.2 Applied Behaviour Analysis

Classrooms for children with autism in Ontario are currently based on the principles of ABA (Ministry of Education, 2007). In 2007, the Ontario Ministry of Education created a policy memorandum, PPM 140, that requires teachers of students with autism to use evidence based practices, such as ABA, in the classroom. This requirement creates more standardized autism classrooms in this study. According to Alberto and Troutman (2009), ABA is a more rigorously defined version of behaviour modification because it includes the requirement to record data as evidence of the effectiveness of the treatment. Behaviour modification is the application of operant conditioning, which is concerned with the relationship between consequences and behaviours, to human behaviour. It was first used in applied settings in the 1960s, but various studies and reviews have been performed since then to support it (Eikeseth, 2008; Ospina et al., 2008; Simpson, 2005). In Ospina et al.'s 2008 review, all of the studies that compared direct trial teaching (DTT), a branch of ABA that involves repeated trials of desired skills, to no treatment had significantly positive results.

Alberto and Troutman (2009) state that both adaptive and maladaptive behaviour is learned, and that this learning occurs as a result of behaviours having consequences. Rewarding consequences following a behaviour that increase the behaviour, such as getting free time for completing a task, are considered positive reinforcement. According to Alberto and Troutman, reinforcement is the key behind ABA. Punishment occurs when a consequence after a behaviour decreases that behaviour. Extinction is used in the classroom instead of punishment to decrease behaviour. This involves discontinuing the reinforcement of undesired behaviours, such as no longer giving a toy when a child screams for it. Antecedents, or events that come before a behaviour, also have an impact on behaviour.

Maladaptive behaviours can be observed and tracked for weeks before an intervention program is attempted. All behaviours are thought to occur for one of four reasons: avoidance, attention, tangible acquisition (such as getting a toy), and sensory (usually the pleasure of the behaviour itself) (Alberto & Troutman, 2009). In applied behaviour analysis, programs are not based on the behaviour, but on the motivation for the behaviour. For example, if a student is screaming, the program will depend on whether the student is screaming to avoid doing a task, to get attention

from the teacher, to get a toy, or because they enjoy the feeling of screaming on their ears. Behaviours are also replaced with another behaviour, such as verbals, sign language, or picture card communication. For example, if a student is screaming for a toy, they will not get the toy. Instead, they will be prompted to ask for the toy with a picture card. When they do, they will get the toy. Eventually, the student will learn to ask for the toy and will extinguish screaming after repeated trials.

Behaviours must be measurable and observable. This not only includes undesired behaviours, but also desired behaviours, such as reading. DTT is one of the best known strategies in applied behaviour analysis (Alberto & Troutman, 2009). It is a form of one-to-one teaching frequently done in a cubicle setting using repeated trials of prompting and reinforcement to teach students new skills. According to Alberto and Troutman, prompting is the help given to a student to complete a task once the request has been given. Prompts include full and partial physical (moving the student's hand to the required letter card), gestural (pointing to the right card), positional (putting the right card closer to the student), visual (showing a picture of the desired card), and various levels of verbal (full, partial, and indirect). These prompts are different levels of support, and they should be faded until the task is acquired independently.

1.1.3 Disability Theory and Autism

An understanding of the models of disability and how they relate to autism is necessary to grasp the interpretive theory used to frame this research. Before 1980, the medical model was the dominant model of disability (Barnes, Oliver, & Barton, 2002). Siebers (2008) reminded us that disability had been based on a medical issue for as long as humans had dealt with disease, injury, and death. The medical model looked at disability as a problem of impairment in the individual (Siebers, 2008). The United Nations' (2004) definition of impairment was “any loss or abnormality of psychological, physiological, or anatomical structure or function”.

The social model focused on the social construction of disability by social or environment barriers that hampered people with impairments (Barnes et al. 2002). Siebers (2008) argued that disabling environments produce disabled bodies, and that interventions are required at the level of social justice. The article argued that the social model of disability does not attempt to cure disability or disease. Its goal is to study and intervene on enforced system of exclusion and

oppression of disabled people. Thomas (2002) claimed that since disability was defined as a form of social construction, “disablism” referred to a type of social oppression, like sexism and racism. In the social model, the term “disability” is no longer synonymous with “impairment”, but is the effect of a disabling environment on a person with an impairment (Patterson & Hughes, 1999).

Although Barnes et al. (2002) argued that the social model does not deny impairment, there are those who deny the impairment and say that disability is only a social construction that could be eradicated if society took disabled people into account (Reindal, 2008). Cole (2007) claimed that the purpose of the social model not addressing impairment is political, because it could detract from the message of the social construction of disability required for the disability movement.

Theorists have found that neither the medical nor the social models of disability adequately represented the lived experiences of people with disabilities (Allan, 2010; Anastasiou & Kauffman, 2011; Wendell, 1996; Vedder, 2005). McClimens (2003) pointed out that many people with intellectual disabilities feel excluded from a model of disability designed around people with physical disabilities. The article claimed that the social model could be oppressive to certain sectors of people with disabilities. Some theorists suggested models that move beyond simply adding personal experiences of impairment to the social construction of disability (Clare, 2009; Shakespeare & Watson, 2001). They argued that there are aspects of disability that neither medicine nor modifications to the social environment can alter, such as pain (Hughes, 2002; Siebers, 2008).

Autism is problematic for disability theory, and people with autism are often left out of the discussion of a model of disability. Anastasiou and Kauffman (2011) claimed that the social model is unable to encompass every single disability, and it is unclear what social barriers should be removed to accommodate the needs of people with autism. For example, there is fear and pain that results from seizures. Seizures can become more acceptable to people in society and we can create environments to reduce seizures, but seizures will still be scary and painful for those who experience them. Likewise, when people with autism experience communication difficulties, even with communication devices, there are still needs and wants that people with autism are often unable to communicate. Watson (2012) points out that even if we can make it

possible for people with autism to participate, there are also some children who may not wish to participate. Because autism is problematic for disability theory, autism education also becomes problematic. Education creates change not just in the social environment, but in the individual. In this way, it appears to follow both the social and medical models of disability. Considering the models of disability can help in the decision-making process when planning programs for students with autism. For example, if a student will not wear mittens outside, consider if wearing mittens is a social or medical issue. If the temperature requires mittens for comfort instead of safety, perhaps the way the child perceives cold is not uncomfortable, or at least does not outweigh the discomfort of mittens, and the child does not require mittens. If wearing mittens is a safety issue, when frostbite is a possibility, and the child otherwise enjoys the out-of-doors in winter, a mitten wearing program based on a medical model would be acceptable, but the environment can still be changed to make this less painful for the student by attempting to find a texture and thickness that is most comfortable to the student.

Both Patterson and Hughes (1999) and Thomas (2004) began the conversation about a new model of disability by respectively dividing social disability into “active” or “passive” disabling or into external barriers to doing and internal barriers to being, in addition to impairment effects. What they both mean with their differing language is that the new model of disability includes physical social barriers and emotional social barriers in addition to medical barriers. But, Watson (2012) claimed that impairment and disablement are a complex interwoven matrix, and there was concern that they may be seen as a dual system. Shakespeare and Watson (2001) asked where impairment ends and disability starts to demonstrate that a model of disability should be more complicated than the disability /impairment dichotomy. The duality between constructed disability and medical impairment is blurred (Clare, 2009). Shakespeare and Watson (2001) argue that there is no qualitative difference between people who are defined as disabled and people who are not, because we are all impaired to a degree. They acknowledge that there are profound differences between the two groups, but that the differences are still a matter of degree and are not two distinct ontological statuses. Shakespeare and Watson consider the social model a “modernist project”, and claim that we now need to look from a postmodern perspective.

Shakespeare and Watson (2001) argued that the priority of a model of disability should be social change, not medical research, but they support appropriate action and prevention on impairment.

They point out that removing environmental obstacles for one person with one impairment may well generate obstacles for another person with a different impairment. This would be the case if a child with autism with loud stereotypic behaviours and a child with autism with a hyper-sensitivity to noise were to share the same inclusive space. A space can be made acceptable for noise for one child, or quiet for another, but not both at the same time if it is to be truly inclusive.

Silverman's (2008) review of social science research on autism claimed that the most successful studies are those that refuse to situate their claims firmly within the social or medical models, but instead focus on the strategic uses of the different models by various interest groups.

The review of the literature on the impact of a child with autism on parents can be looked at from a disability theory perspective as a starting point for this analysis. Looking at the qualitative research on parents of children with autism, one of the most common themes content coded in the literature review was society's lack of understanding and acceptance (Bundy & Kuncie, 2009; Meirsschaut, Roeyers, & Warreyn, 2010; Myers, MacKintosh, & Goin-Kochel, 2009), which was coded by eight of the papers. Woodgate, Ateah, and Seccon (2008) claimed that parents felt that society valued their children with autism less than other children. This lack of understanding went well beyond society as a whole, and included strained relationships with family (Hall & Graft, 2010; Myers et al., 2009; Woodgate et al., 2008), the church community (Altiere & Von Kluge, 2009; Phelps, Hodgson, McCammon, & Lamson, 2009), friends (Myers et al., 2009; Papagergiou & Kalyva, 2010), and schools and services (Bundy & Kuncie, 2009; Myers et al., 2009). Although parents wanted to improve services, their main goal was to gain acceptance and recognition from others for their children (Altiere & Von Kluge, 2009).

The other most common theme content coded in the qualitative literature on parents of children with autism in the literature review was the need for support and services, which was also coded by eight papers. The system was considered "unsupportive" and "inaccessible" (Altiere & Von Kluge, 2009; Meirsschaut et al., 2010). Services such as education and medicine were found to be lacking in knowledge, and parents suggested that educators and medical professionals were educated (Hall & Graft, 2010; Phelps et al., 2009; Woodgate et al., 2008). The financial cost of having a child with autism (Bundy & Kuncie, 2009; Papagergiou & Kalyva, 2010; Phelps et al., 2009), including employment effects (Altiere & Von Kluge, 2009; Myers et al., 2009), shows a

clear need for support for parents. Even themes such as time demands (Myers et al., 2009), pervasiveness of autism in life (Meirsschaut et al., 2010; Myers et al., 2009), sleep problems and exhaustion (Myers et al., 2009), missed activities (Bundy & Kuncie, 2009; Myers et al., 2009), neglected siblings (Altiere & Von Kluge, 2009; Bundy & Kuncie, 2009; Myers et al., 2009), and marital strain (Myers et al., 2009) can be seen as a need for support in the form of relief. One parent, when discussing marital strain, said she needed respite care (Myers et al., 2009). Another parent, talking about living in a world her own, felt like she had to “go it alone” (Woodgate et al., 2008). Parents felt like they needed to fight to get services (Altiere & Von Kluge, 2009).

When parents specifically addressed a lack of understanding and acceptance or a need for support and services as above, they are clearly working from a social model of disability. Maladaptive behaviour is the most common child variable content coded in the literature review (Papageorgiou & Kalyva, 2010; Phelps et al., 2009), with seven papers including codes on maladaptive behaviour. Parents see this as both an impairment and a socially constructed disability. Parents have listed behaviours including aggression, fecal smearing, extended screaming (Hall & Graft, 2010), “tormenting” siblings, violence with police involvement, physically assaulting a child under five years old several times, aggression requiring hospitalization, living in fear of a child taking their life or losing it to poor judgement (Myers et al., 2009), obsessive and perseverative behaviours, and tantrums (Bundy & Kuncie, 2009). From the language used to describe the behaviours above, it is clear that these behaviours are impairments for parents, and are from a medical model perspective. On the other hand, parents claim that people look at their children with autism like “aliens” during behaviours in public (Hall & Graft, 2010), and parents feel blamed by strangers for their child's behaviours (Papageorgiou & Kalyva, 2010). Hall and Graft (2010) point out that child maladaptive behaviours contribute to the social isolation of parents, but that this is related to limited respite and support. Therefore, it is not only the behaviour as an impairment that creates isolation, but the society that disables the child by not understanding and accepting their behaviours in public. This is reinforced by Gray’s (2002) claim that parents of aggressive children are more likely to experience stigma than the parents of other children. Boyd’s (2002) claim that behavioural problems may present more of a challenge than cognitive difficulties because of the potential public scrutiny that parents face from society and their social circles also reinforces this.

There were two themes in the qualitative literature on families of children with autism that were talked about from the perspective of a medical or individual model, and they were emotional well-being and communication (Bundy & Kuncie, 2009; Hall & Graft, 2010; Myers et al., 2009; Papagergiou & Kalyva, 2010). The emotional difficulties were fear, anxiety, panic attacks, uncontrollable rage, and emotional well-being (Bundy & Kuncie, 2009; Hall & Graft, 2010). Myers et al. (2009) included the fact that a child didn't speak as a behaviour, and Hall and Graft (2010) quoted a parent as saying that her child looks at her like he wants to tell her something, but he doesn't have the words.

Many of the other student variables are neutral, without hinting as to whether it is the impairment or society's lack of understanding and support that causes the stress around them, such as difficulties with self-help (Bundy & Kuncie, 2009; Papagergiou & Kalyva, 2010), motor difficulties (Bundy & Kuncie, 2009), difficulties with social skills (Bundy & Kuncie, 2009), and worry about the child's future (Bundy & Kuncie, 2009; Hall & Graft, 2010; Phelps et al., 2009).

Although the literature used some medical language while talking about the effect of a child with autism on the family, such as wishing for or missing a “normal” child or life (Altieri & Von Kluge, 2009; Bundy & Kuncie, 2009; Woodgate et al., 2008), wanting a “cure” (Bundy & Kuncie, 2009), wanting to “fix” the child's problems (Myers et al., 2009), claiming there is something “wrong” with the child (Altieri & Von Kluge, 2009), and asking about etiology (Altieri & von Kluge, 2009; Hall & Graft, 2010), and although there were some aspects of autism that were seen as medical, such as some behaviours, emotional difficulties, and communication, this was outweighed by the desire for understanding, acceptance, support, and services by parents of children with autism.

There are two distinct forms of social construction recognized by parents, called here a lack of understanding and acceptance and a lack of support and services. There are also aspects of autism that are recognized as based on impairment. The model of external and internal barriers impacting physical and psycho-emotional aspects of disability along with “impairment effects” (Thomas, 2004) would be most reflective of the way parents view autism in the review of the literature on the impact of a child with autism on parents.

1.2 Effects of Summer Break on Student Achievement

The purpose of this review of the literature on the effects of summer break on student achievement is to relate the effects of summer break on students with special needs to the effects of summer break on students in the general population, as well as the fall recoupment time of students with special needs to the fall recoupment time of students in the general population.

This review begins by looking at summer regression in the general population, then summer regression in the special needs population, and finally the fall recoupment research for both populations. Summer regression research in the general population is divided into three sections: summer effect research, summer as a control for school effect studies, and summer program study control groups. Only literature on school effectiveness that used summer as a control for the school year was used, because this review was only concerned with learning or regression over the summer, not the effect of school during the school year, and only literature on school programs that had a control group who did not get programming in the summer were used because this review was only concerned with regression over a break, not the quality of summer programs. Within each of these sections, the paper is organized based on achievement area, and within these on the chronological development of the research, as later research builds upon previous research. Finally, the section ends with a discussion of the implementation of assessment in the research.

The articles for this review of the literature were found by searching the Eric, PsycInfo, and Sociological Abstracts databases with search terms including “summer regression”, “summer effect”, “summer learning”, “summer slide”, as well as summer AND break, vacation, school, education, achievement, recoupment, and retention. Journal articles, books and book chapters, information and opinion articles, dissertations, and government publications from before 1975 to the present were found on the subject. Publications found from before 1975 were not used in this review unless they were of historical interest because of Cooper et al.'s (1996) assessment that studies before 1975 may not be relevant to students today, and they were of uneven quality. The bibliographies of the most relevant and recent literatures were searched for articles missed in the database searches. The list of articles that cite Cooper et al.'s meta-analysis of the effects of summer vacation on achievement test scores was also searched.

1.2.1 Summer Effect Research in the Regular Population

A review of the literature on summer regression starts with Cooper et al.'s (1996) analysis of the effects of summer vacation on achievement test scores in 39 studies. They found that 26 studies done before 1975 did not have enough information to include them in their meta-analysis, so they simply synthesized the results using a vote-count based on the direction of the results. The vote count found that overall regression over the summer was not significant, but there were significant losses in the subject areas of mathematical computation ($p < 0.01$) and spelling ($p < 0.01$) over the summer months. All of the studies that looked at these areas found losses. Cooper et al. (1996) found 18 articles based on 13 studies between 1974 and 1994. They used 14 of the articles to create a meta-analysis without overlapping data. They performed their meta-analysis by calculating a standardized mean difference (d) and the difference in grade level equivalents (DGLE). They then calculated average effect sizes using both weighted and unweighted procedures. Cooper et al. reported on the results with and without the Klivanoff and Haggart study because, with a sample size of 38,384, this study was so large that it overwhelmed the rest of the samples in weighted calculations. The overall effect of summer break on student achievement in Cooper et al. (1996) was $d = -0.09$ and $DGLE = -0.09$ (about one month) with an unweighted calculation and $d = 0.02$ and $DGLE = -0.13$ when weighted. The positive d -index in the weighted calculation was attributed to the large Klivanoff and Haggart (1981) sample that had unusually high positive results. The d -index without that data was $d = -0.10$ with an unweighted calculation or $d = -0.13$ with a weighted calculation. Cooper et al. summarized that students at best demonstrated no academic growth over summer and at worst, lost one month of grade-level equivalent skills relative to national norms, or one tenth of a standard deviation.

The average weighted d -indices of various subject areas showed that summer break had a significant negative effect on student achievement in mathematics computation ($d = -0.32$) and total mathematics ($d = -0.18$) without the Klivanoff and Haggart (1981) study, and on reading comprehension ($d = -0.19$), spelling ($d = -0.41$), and total reading ($d = -0.15$) without Klivanoff and Haggart. Cooper et al. (1996) also gave the average weighted d -indices of subject areas for which summer break had a significant positive effect: mathematics application ($d = 0.17$), vocabulary ($d = 0.12$), and total reading with Klivanoff and Haggart (1981) ($d = 0.08$). Their study also revealed that students from middle-class and lower-class families had the same negative

effects from summer break on math, but lower-class students had greater negative effects of summer break on reading skills. After Cooper et al.'s (1996) meta-analysis, much of the summer regression research moved toward specific populations of students, such as students from low socio-economic status families, bilingual students, or students with intellectual disabilities. Another emergent branch of research, now that Cooper et al.'s findings of one-month summer regression was being referenced frequently in the area of summer regression research (example: Alexander et al., 2001; Borman et al., 2005; Burkam et al., 2004; Helf et al., 2008; Kim & White, 2008; McCoach et al., 2006; Verachtert et al., 2009), was research into summer programs as solutions for summer regression. The control groups for these studies gave data on summer regression. Finally, summer became used as a control for the school year to calculate the effect of schooling, giving data about either absolute or relative regression in the summer. This section looks at the research on summer regression, starting with regression in comprehensive achievement first, and then moving on to research specifically on language and literacy.

Phillips and Chin (2004) looked at 1,141 first graders who took the Comprehensive Test of Basic Skills. The purpose was to determine how students, families, and teachers impact summer learning. Phillips and Chin found that, on average, first graders gained significantly on all subtests over the summer. However, because the average testing interval was 169 days, which is longer than the actual summer break of approximately 70 days, some of these gains may be a result of schooling after the pre-test but before the break or after the break but before the post-test. Phillips and Chin also claimed that teachers' ability to show students and their parents how to learn over the summer may be relevant. When children read more, and are read to, their verbal skills improve over the summer, however, this does not explain gains in other academic areas.

Lai, McNaughton, Amituanai-Tolosa, Turner, and Hsiao (2009) included summer data to see if summer effect could be overcome in their investigation of a summer program in New Zealand. They looked at students in grades four to eight over three years tested six times at half year intervals on the Progressive Achievement Test and the Supplementary Tests of Achievement. They found that growth was not smoothly linear or quadratic; they called it "staircase shaped". They explained this staircase as a result of the tendency for achievement to plateau over summer and for gains to be made during the school year. They found a plateau rather than a drop over the

summer.

Although some researchers looked at the effect of summer break on overall achievement, others looked at the effect of summer break on language or literacy. One of the aims of Hammer, Lawrence, and Micco's (2008) research was to determine how a lengthy summer vacation affected bilingual children's language development. The summer break was four months in this study. Based on the research on the reading abilities of low-income children previously reviewed, it was hypothesized that four months of summer break would have a negative impact on students' English receptive language skills. The study looked at 83 bilingual children from Spanish speaking or Spanish/English speaking homes attending Head Start classrooms. Students' receptive language skills were assessed in the spring and fall of the students' two years in Head Start. Hammer et al. (2008) concluded that the four-month summer break had a differential effect on student's abilities between academic years depending upon whether the students' scores increased or decreased when attending school in English during the school year. Student scores that went up during the school year went down over the summer, and vice versa.

Helf, Konrad, and Algozzine (2008) looked at 151 students in kindergarten through second grade. The purpose of their study was to research the effects of summer break on early literacy skills. On four tests of early literacy development from the Dynamic Indicators of Basic Early Literacy Skills, fall scores were higher than the preceding spring scores for all students in all areas except letter naming fluency. There was no regression in any area over a 10-week summer break for this sample of students, most of whom were struggling readers.

Zvoch (2009) followed 3,485 kindergarten students for two years through first grade to compare learning of full-day and half-day kindergarten students in literacy to see if full day kindergarten would help economically disadvantaged students. The full-day economically disadvantaged kindergarten students gained faster in kindergarten, but during the summer break economically disadvantaged full-day students began to regress compared to their more advantaged half-day counterparts in a similar way to the time prior to the start of kindergarten when they were not in school. (Economically disadvantaged students started school at a lower level.) According to Zvoch, economically advantaged half-day students maintained their skills over the summer.

High-achieving and average students were compared by Rambo-Hernandez and McCoach (2015)

by looking at 171,380 grade three students over three years. Students were assessed using the Measures of Academic Progress in Reading in the fall and spring of each year of the study. Average students stayed the same over the summer break, but students in the top 10% increased more slowly during the school year and maintained this growth over the summer.

Research after Cooper et al. had similar results to research included in Cooper et al. In reading, the majority of studies reported gains (Helf et al.; 2008, Phillips & Chin, 2004) or no change (Hammer et al, 2008; Lai et al., 2009). The losses were found in low socio-economic students (Zvoch, 2009). High-achieving students made gains (Rambo-Hernandez & McCoach, 2015). Only one of the studies focussed on math, and found gains (Phillips & Chin, 2004), but the gains may have been found due to the length of the testing interval.

1.2.2 Summer as a Control for School Effect Studies

Heyns (1978) used summer as a control for school effect, with summer being the absence of school, and since then there have been many studies that have been based on her research (Alexander et al., 2001, 2007; Burkam et al., 2004; Downey et al., 2004; Verachtert et al., 2009). Heyns' study was a response to the often referred to “Coleman Report” of 1966, which argued that schools were increasing the achievement gap between socio-economic classes. Heyns demonstrated that this gap grew in the summer, and the schools actually helped even out the inequality by teaching students at similar rates. Heyns demonstrated that low socio-economic status (SES) children showed a higher rate of relative achievement during the school year than during the summer break. Heyns found that the gap between black and white children, and between low SES and high SES children, widened disproportionately during the summer break. This showed that the achievement of high SES students was not as dependent on the influence of schooling as was the achievement of low SES students. Most of the research on school effect used literacy levels to measure school effect. This section looks at the research that uses literacy and math.

Alexander, Entwisle, and Olson (2001) looked at 790 students over 5 school years. The purpose of their research was to determine if there were SES differences in student learning over the school year and summer break. They found that reading scores of lower SES youth plateaued over the summer, while in mathematics lower SES students regressed. This means that lower

SES children generally start the new school year about where they had been the previous spring or even lower. Upper SES students improved over the summer months in both areas so they entered school at a higher level than they ended the year before. However, Alexander et al. point out that both groups made similar gains over the school year.

Burkam, Ready, Lee, and LoGerfo (2004) looked at 4,423 students between kindergarten and the first grade. They found that children from high SES families learned more over the summer than low SES family students. Overall, there were no average gains in summer literacy. Children in the middle SES group exhibited no summer gains in literacy, but low SES children regressed and high SES children made gains. In math and general knowledge, middle SES students gained significantly, while high SES gained more and low SES gained less. They also found that summer activities showed only modest relationships with students' learning in the summer between kindergarten and the first grade.

McCoach, O'Connell, Reis, and Levitt (2006) examined the impact of student and school characteristics on reading growth during the school year and summer break. They used two years of kindergarten data from the Early Childhood Longitudinal Study of 8,089 students. They found that on average, students from high SES backgrounds experienced small but statistically significant reading growth, and students from low SES backgrounds experienced small but statistically significant reading regression over the summer break.

Downey, von Hippel, and Broh (2004) looked at both reading and math to research school effect. Downey et al. (2004) studied 17, 212 children who started in kindergarten. They looked at the inequality in seasonal learning, and found that students learned at much more equal rates during the school year than over the summer break. Students on average gained 0.51 points/month in math in the summer as compared to 1.31 to 1.54 points/month in school ($p < 0.01$). They did not gain in reading over the summer, but gained 1.65 to 2.52 points/month in school ($p < 0.01$).

Verachtert, Van Damme, Onghena, and Ghesquiere (2009) looked at the math skills of 2,987 children in Belgium. The purpose of their research was to examine whether schooling had absolute effects on math, and if this school effect was different for different groups, such as SES. They found steeper gains during the school year than over the two-month summer. They did not, however, find a difference in summer learning rates between different SES groups.

Looking at school effect research to determine summer regression has shown that students learn more during the school year than during the summer (Alexander et al., 2001; Burkam et al., 2004; Downey et al., 2004; Verachtert et al., 2009). There is also much agreement that students from low SES groups regress significantly more, or gain less, over the summer break than high SES students (Alexander et al., 2001; Burkam et al., 2004; Downey et al., 2004, McCoach et al., 2006). Verachtert et al. (2009) were the only researchers who did not report these findings, but their research was done in Belgium, where SES may have a different impact on education than in North America. Some studies reported no change in reading over the summer (Downey et al., 2004) and gains in mathematics (Burkam et al., 2004; Downey et al., 2004) in the overall population, but losses in reading (Burkam, 2004; McCoach, 2006) and mathematics (Alexander et al., 2001) in the low SES population. This data has raised the question of whether looking at the regular population alone may be applicable to students with special needs, because it is less applicable for students from low SES families.

1.2.3 Summer Program Study Control Groups

Many studies on the effectiveness of summer programs such as summer school, extended school year, and year round schooling have been conducted. Summer school is an extra program or intersession class offered in the summer, extended school year is a longer school year including more than 200 days extending into the summer, and year round schooling is a school year of the same number of days spread out to create more but shorter breaks from two to eight weeks long (Ballinger, 2004). The studies which used control groups of students who did not attend such programs, which tested the control group before and after the summer break as a comparison for the experimental groups, and which reported on the change between the pre-test and the post-test provided information useful to this literature review because, for the purposes of summer effect research, only data examining the effect of the summer break was considered useful. All of these studies were on summer school type programs, because extended and modified school year studies often used year round data instead of spring to fall data. In these studies, the data on the control group itself represented absolute gains or losses, while the comparison of the control group to the treatment program represented relative gains or losses.

North American schools have a school year of approximately nine months, with a summer break

of up to approximately three months (Ballinger, 2004). According to Ballinger, this was the result of families historically requiring their children to work on farms during the early years of formal schooling in North America. American schools have a longer summer break than most other national schools, which often spread breaks out throughout the year (Wiseman & Baker, 2004). In America, according to Wiseman and Baker, learning retention, and even enhancement, is more likely for students from high socio-economic families, while children from low socio-economic families regress over the summer break. Wiseman and Baker, in their review of the literature on summer learning in nations outside of America, found that the summer learning gap was not an issue in other nations.

Another meta-analytic and narrative review of summer programs was published by Cooper, Charlton, Valentine, Muhlenbruck, and Borman (2000) as one of three planned reviews of summer school, extended year schooling, and year round schooling. They looked at summer program research up to 1998. They concluded that students in summer programs could be expected to score between one seventh and one quarter of a standard deviation higher than the control group. They pointed out that a specific summer program might yield a very different effect from their overall findings. They also found that summer school had a larger effect on middle SES students than low SES students, on early primary and high school grades than on middle grades, and on mathematics than on reading. Most of the research since Cooper et al.'s (2000) narrative and meta-analysis has been on summer programs in literacy. This section of the review looks at summer programs for literacy, before moving on the summer programs for math.

Multiple papers were written on the Teach Baltimore program by Borman and colleagues (Borman & Dowling, 2006; Borman, Benson, & Overman, 2005; Borman, Overman, Fairchild, Boulay, & Kaplan, 2004; Borman, Rachuba, Hewes, Boulay, & Kaplan, 2001) looking at the effectiveness of the program in preventing summer reading loss for early elementary students in high poverty schools over three years. The Teach Baltimore program ran from 1999 to 2001 and involved a six-week full day academic summer program. Assessments were performed with the Comprehensive Test of Basic Skills each spring and fall. Borman et al. (2001) looked at 293 kindergarten and first grade children who attended the program and 135 who were randomly assigned to the control group during the first year of the program. In the kindergarten cohort, the treatment students made larger reading achievement gains than control group students, and the

grade one treatment group made smaller losses than control group students, but neither result was statistically significant. Even when actual treatment, as opposed to treatment assignment was taken into account due to the low attendance at the programs, statistical significance was not reached. Borman et al. (2004) looked at 290 kindergarten students who attended Teach Baltimore in two cohorts and 182 control students over the three summers. There were no significant differences between the treatment and the control group for the first two years of either cohort, but the effect sizes grew each summer until by the third year of the first cohort there was a statistically significant effect size ($d=0.24$) for the treatment group. In the third year of the program the control group made both absolute and significant relative losses. Borman et al. (2004) concluded that multi-year intervention is more effective than single year summer intervention. Borman and Overman (2005) found that, based on 303 of the students, the average of students assigned to Teach Baltimore (whether attending or not) and control students lost 0.10 standard deviations from spring to fall on the reading achievement test, but students with full attendance had a program effect size of 0.27. Borman and Dowling (2006) found that, based on all 438 Teach Baltimore students and 248 control students, when low SES students did not get programming in the summer they experienced summer achievement loss or limited gains, and students with full attendance had a program effect size of 0.30.

The six-week full day KinderARTen Camp program was studied by Borman, Goetz, and Dowling (2009), which included 93 low-SES students who took part in the program and 35 control students. They used the Dynamic Indicators of Basic Early Literacy Skills, Developmental Reading Assessment, word lists, and dictation for testing. There were statistically significant positive effect sizes for word list reading ($d=0.27$) and Developmental Reading Assessment ($d=0.40$) for the treatment group and no significant effect sizes in the other three areas of letter naming, phoneme segmentation, and dictation. When actual participation in the program was considered instead of just assignment to the program, the effects of participation for the statistically significant areas goes up to an equivalent effect size of $d=0.36$ and $d=0.51$ respectively. In these two areas, the control group makes significant relative losses, but they only experience absolute losses in the word list. One cause of possible low effect sizes in the other three areas is difficulties with first-year summer program implementation, such as nearly half of the program teachers feeling unprepared to implement the reading curriculum. Borman, Goetz, and Dowling (2009) do not know how these difficulties affected treatment.

Schacter and Jo (2005) compared 72 low SES first graders who attended a seven week full-day summer reading camp intervention with 90 control group students. They used the Gates-MacGinitie decoding and comprehension sub-tests and the Stanford 9 decoding and comprehension tests to assess the students. The control students made gains in decoding and losses in comprehension over the summer break, but treatment students increased 33% in decoding and 41% in comprehension compared to controls by the end of the summer. Schacter and Jo also found that these benefits diminished over time, with 0% difference in decoding between treatment and control by the following May. They suggest that this diminished benefit could be the result of teachers re-teaching skills they already know for the benefit of students who did not have intervention.

Kim and White (2008) looked at 401 kindergarten to grade six students over a summer who were put in one of four groups: a control group, a free books only group, a books with oral reading scaffolding group, and a books with oral reading and comprehension scaffolding group. Students were assessed with both the Iowa Tests of Basic Skills vocabulary and reading comprehension sub-tests and the Dynamic Indicators of Basic Early Literacy Skills oral reading fluency subtest. Kim and White found that there was no difference between control students and students who received books over the summer. Although the control group did progress slightly, the books with oral reading and comprehension scaffolding group did significantly better with an effect size of 0.14. Later, when a similar study was performed by Kim and Guryan (2010) using 370 low-income grade four Latino children who were over 90% Spanish speaking at home, even parent training was not enough to significantly affect reading achievement, and both treatment and control groups regressed on the Gates-MacGinitie Reading Test. The research by Kim and colleagues was interesting because the control groups could be used to show absolute progress or regression of students over summer break.

Haymon (2009) looked at summer programs in reading, writing, and math (2009). The study compared 30 sixth graders who attended a six-week full day summer school program and 30 control students and assessed them using the Terra Nova Complete Test Battery. Treatment students had statistically significant gains in writing and reading, but not in mathematics. Control students did not have any statistically significant changes. No statistically significant long term gains were found at the end of grade seven in any area.

A recent study on a summer reading program looked at 13 students in grades one to three who participated in the three week long reading program and 35 who did not (Johnston, Riley, Ryan & Kelly-Vance, 2015). All students were from one primarily low-SES school. Students were assessed using the AIMSweb oral reading fluency assessment at the end of the school year, the beginning of the program, the end of the program, and the beginning of the following school year. Comprehension was also assessed during the program, but not during the school year, so it would only show the progress of the three-week program, but not the overall impact over the summer break. While the participants made up for the summer loss, the control group showed a significant decline in achievement over the summer break.

The only research exclusively on summer programs in math that fit the criteria for this literature review was by Bianco-Sheldon (2007). Bianco-Sheldon (2007) looked at 33 nine to thirteen-year-old students who were either tutored in mathematics in small groups or individually for 60 minutes a week for seven weeks and 46 control group students. They were assessed using the Great Source Education Group's Summer Success: Math textbook. The control group experienced losses in mathematics over the summer, and the students who received tutoring improved significantly. Tutoring also produced significant gains in the individual mathematics subcategories of number sense, basic operations, geometry and measurement, patterns and algebraic reasoning, and problem solving and data analysis.

In summary, the control groups in the above summer program studies made relative summer reading losses (Borman et al., 2009; Borman & Dowling, 2006; Borman & Overman, 2005; Haymon, 2009; Johnston et al., 2015; Kim & White, 2008; Schacter & Jo, 2005) and no overall change (Borman et al., 2001, Borman et al., 2004; Kim & Guryan, 2010). The control groups also experienced relative summer mathematics losses (Bianco-Sheldon, 2007). The research above reinforced Cooper et al.'s findings of overall mathematics and reading losses.

1.2.4 Summer Effect Research in Special Education

Cooper et al. (1996) claimed that the summer break could have a greater negative impact on the achievement of students with special needs, and that many states required shorter summers for these students because they recognized this need for summer programming. Shaw (1982) claimed that results of summer regression research with the regular population may not have

applied to students with special needs, and Cooper et al. seemed to agree with this when they claimed that although no relationship had been shown to exist between intelligence and summer regression, this should not be generalized to students with abnormally high or low IQ scores or to students with special needs.

Although much of the summer regression research as far back as 1927 included information about intelligence by using IQ (Cooper et al., 1996), special education summer regression was not specifically studied until 1977 (DeVito & Long). Although the Cooper et al. meta-review covered much of the summer regression research that appeared over the last nearly 100 years, Cooper claimed that effective research was written on the subject starting in 1975. A search of the databases for this research provided several other articles that appeared during that time. They were in the areas of special education or closely related to special education, such as compensatory education programs for students at risk (DeVito & Long, 1977). Shaw (1982) was the only researcher in Cooper et al.'s meta-analysis who looked at special education summer regression. This section of the literature review looks at the effects of summer break on students with special needs, starting with research on the effects of summer break on literacy and math skills, and ending with research on the effects on adaptive skills and behaviours. All studies are from the United States except for the Handleman and Harris 1984 study from Australia. Many of the earlier studies used the language “handicapped” for developmentally delayed or physically impaired. This language has been maintained and clarified where necessary.

DeVito and Long (1977) looked at the reading achievement scores of 238 educationally disadvantaged students in second to fifth grade in the spring and the fall. The purpose of their research was to compare the use of spring pre-tests and fall pre-tests on the effects of compensatory education program evaluation that has a post-test the following spring. A spring pre-test would include the summer effect in the evaluation of the compensatory education program, while a fall pre-test would not. They found a decline in mean Achievement Development Scale Scores for reading for all grade levels from the spring of one grade to the fall of the next grade. At three of the four grade levels (grades 2, 4, and 5), these declines were statistically significant at the 0.01 level. DeVito and Long concluded that their study provided some empirical evidence of summer drop in reading achievement.

The purpose of Cornelius and Semmel's (1982) study was to research the regression of reading skills of students with learning disabilities, and to research the effect of a five-week reading program on these students. They looked at grade three to eight students in learning disabled classes with average intelligence who were two or more years below grade level in reading. The participants included 15 students who attended a five-week summer reading program during the first five weeks of summer, 15 students who attended a five-week summer reading program during the last five weeks of summer, and 30 students who did not receive any formal reading instruction during the ten-week summer break. Each summer program involved one hour a day for five weeks. They used the Slosson Oral Reading Test as a pre-test in June and a post-test in September.

Cornelius and Semmel (1982) found that raw scores dropped from June to September. They also found that there was no significant difference between the June and September scores of the students who attended one of the summer programs. Students with learning disabilities regressed in their reading skills when they experienced extended breaks and a five-week summer reading program during either the first or last half of the summer minimized this regression.

What was not discussed in Cornelius and Semmel (1982) is that students in all three groups lost approximately three months in terms of grade equivalent scores in reading during their respective breaks during the summer. The control group had a break for the whole summer, lasting approximately ten weeks, but the two experimental groups only had breaks of five weeks, because the other five weeks were spent in a summer program. The students in the experimental groups regressed approximately three months during their break, but either recouped these gains during the following summer program or made gains during the previous program before losing them during the break, showing no change on the final post-test. One might expect that a break that was twice as long, as was the break for the control group, would have produced twice as much regression. This could have led to a hypothesis that regression tapers out after a certain length of time. The control group was not tested during the third week of July as were the other two groups, but it would have been interesting to test them to see whether most of the regression was in the first half of the summer break, because this would have given evidence that regression does taper out after a certain length of break.

Beatty (1985) researched if students with learning disabilities experienced what she called a regression/recoupment disability. Beatty looked at the reading of third to fifth grade students who were learning disabled or non-learning disabled. The participants included 30 non-learning disabled, 30 learning disabled students who did not participate in a summer program, and 28 learning disabled students who participated in a summer program of one hour a day for six weeks. Beatty used alternate forms of two sub-tests of the Woodcock Reading Mastery Test in May, September, and October. She found that the experimental (summer program) group made gains during the summer and that the learning disabled control group and the non-learning disabled control group maintained their scores during the summer and gained from September to October.

Franklin (1987) looked at severely emotionally disturbed students aged eight to fourteen from a special day school. The participants were 45 students who attended an eight-week summer school and ten students who did not. Two sub-tests of the Peabody Individual Achievement Test were used for the pre-test and post-test assessment of reading. Franklin found that significant reading skill regression did not occur for either group.

Fox (2008) included education type (special or general education) as a variable in his study on summer regression because the need for continuous instruction for students with special needs is often given as a reason for extending the length of the school year. Fox looked at a subset of the Writing Intensive Reading Comprehension study. The study found that general and special education students experienced similar levels of summer reading comprehension decline. On average, students in the high poverty urban sample declined by approximately 0.24 standard deviations between the end of grade four and the beginning of grade five in reading comprehension achievement. Fox also found that change in reading comprehension achievement over the summer period is largely determined by prior achievement; high achievers at the end of grade four experienced the largest declines and low achievers experienced the smallest declines.

Waugh, Fredrick, and Albert (2009) performed a single-subject design study on the sound and blending skill acquisition of three students ages nine to eleven with moderate intellectual disabilities over two years. They found that each student retained the material differently. One student retained all of the previously taught skills, a second student was able to consistently

identify three of the five sight words and two of the five previously taught sounds, and another student retained only one of the five sight words and none of the five letter-sound correspondences previously taught.

Shaw (1982) researched the impact of summer vacation on reading and arithmetic skills of students with learning disabilities. Shaw looked at the reading and arithmetic skills of students between six years and 12 years from 28 schools. The study used the Wide Range Achievement Test reading and arithmetic sub-tests as pre- and post-tests. The sample used in this study included 128 regular education students, 108 resource specialist students, and 58 learning disabled special class students.

Shaw (1982) hypothesised that there would be significant differences between the retention of reading and arithmetic over the summer vacation among all three groups. There were significant differences ($p < 0.01$) in the retention of reading and arithmetic skills over summer vacation between the two groups of learning disabled students and non-disabled students. Although Shaw calculated regression using absolute raw scores, grade equivalents were also provided. Regular education students made five months growth in reading skills over the summer, while resource specialist and special class students decreased by one month in reading skills. Regular education students and resource specialist students demonstrated a two-month loss of arithmetic skills over the summer break, while special class students regressed by four months in arithmetic. Shaw concluded that reading and arithmetic skills regressed over summer vacation for learning disabled students.

Allinder and Eicher (1994) looked at the spring, fall, and recoupment (five weeks later) reading and mathematics scores of 75 second to fifth graders with mild disabilities. Curriculum-Based Measurement was used for assessment, which Allinder and Eicher claimed was more sensitive to changes in student performance than traditional measures used in other studies. Students with mild disabilities did regress significantly in both reading and math between spring and fall. Allinder and Eicher claimed that this demonstrated that students with disabilities are affected adversely by a long school break. Cortez and Hotard (1984) looked at the May and September reading and math scores of 396 remedial students in grades five to eight. They reported summer regression of one-half year in math remedial students, but minimal to non-existent regression in

remedial reading students.

Allinder and Fuchs (1991) were the only researchers to look exclusively at the effects of summer break on the math skills of students with special education needs in their two studies. They researched the effects of school breaks on the mathematics skills of special education students and low-achieving students. They looked at spring and fall mathematics scores on the Math Computation Test of 44 grade five to seven students who were either low achieving or learning disabled. They found that learning disabled students did not exhibit significant changes in mathematics skills following a summer break, but the low achieving students in grade five had regressed. Allinder and Fuchs suggested that learning disabled students may not have regressed because special education teachers are encouraged to remain on a skill until mastery. This idea was backed up by the fact that the grade five students were all taught at grade level and regressed as a group, while the grade six and seven students were taught at a lower level more representative of the students' abilities, and they did not regress.

In addition to the above research on the effect of summer break on academic achievement, there was also research on the effects of summer break on adaptive skills and behaviour. Menousek (1983) researched the extent of regression of special education students over the summer and the impact of summer school attendance on this regression. The recoupment of these skills were also looked at. The study looked at 67 students who were severely/profoundly or “trainable” mentally handicapped (developmentally delayed). Participants were students who had Individual Education Plan goals in toileting, personal hygiene, eating, dressing, or home living skills, and used the percentage of correct performances on self-help objectives from the Individual Education Plans as his assessment tool. A pre-test in May and post-tests in September, October, and December were used.

Menousek (1983) found that lower functioning students tended to lose skills over the summer regardless of summer school attendance. It was argued that current summer school practices may be insufficient to prevent losses in skills over the summer for lower functioning students. Low functioning students may require a summer program that is similar to the school year program to prevent regression. Initially, Menousek's research seemed to show that summer school was detrimental to the progress of students with special needs, but when summer school

attendance in the study was shown to be highly positively correlated to low functioning level, then the lower functioning was considered to be the reason for the finding.

Wilkins (1983) compared the regression of skills of handicapped students who had parent training service delivery over the summer break to the regression of skills of handicapped students who did not have service delivery over the summer break. Wilkins looked at 15 subjects and 25 control subjects ranging in chronological age from two to twenty-one years and in developmental age from 0.6 to 7.6 years, with 13 of the students being non-verbal and 6 being non-ambulatory, who were considered moderately or severely handicapped. It was found that some students still regressed with parent training service delivery over the summer, but that the regression was less than the previous summer with no service delivery and less than the control group with no service delivery both in number of areas of regression and range of regression in those areas. Wilkins did not provide mean scores or significant differences, but this may have been difficult to do given the various types of assessments used in the research. Wilkins also did not elaborate on which specific skills were assessed, because there were a wide variety of ability levels and a wide variety of assessments to match those ability levels. The assessment instruments used varied according to the severity of each student's disability. These instruments were used to look at overall functioning in the areas of cognition, receptive and expressive language, self-help skills, fine and gross motor skills, social skills, and vocational skills. Students were assessed with the same instruments in June and September.

Allen (1984) looked at the effects of summer break on students with special needs who were predicted to not demonstrate fall recoupment. Allen looked at 45 severely multiple handicapped students who attended an extended school year program and 13 severely multiple handicapped students who experienced a 12-week interruption in programming. All students had severe multiple handicaps and IQs below 50.

It was found that 54% of the behaviours evidenced regression while 17% maintained baseline performance status and 29% demonstrated improvement. She concluded that 12 week breaks in programming had a greater negative effect on performance than short 3 week breaks, with motor skills more severely affected than communication and behaviour. Also, six to seven years old students who had programming for under a year were more severely affected by the breaks.

Handleman and Harris (1984), in the first summer regression study of children with autism, looked at four boys with autism between eight and ten years old who showed severe language deficits and disturbed interpersonal relationships. The boys could all imitate sounds, words, and short phrases, but rarely used spontaneous vocalizations. Handleman and Harris tested the boys with two sets of picture cards by teaching the cards to 80% accuracy, and then creating a mock “summer” of nine weeks with one of the sets by not maintaining them. After the mock “summer”, the students were tested on both the maintained and unmaintained cards, and all four students regressed on the unrehearsed cards. Handleman and Harris claimed they found modest empirical support for severely developmentally disabled children requiring ongoing review of material to retain information. They pointed out that the most advanced student mastered the sets more quickly and retained the sets better over time than the less advanced students. Handleman and Harris claimed that there was a frequent observation that the more handicapped a student, the more support the student required to retain skills, and that their conclusions suggested that this was true.

There are many concerns with Handleman and Harris' (1984) research because of a small sample size and the fact that they did not use a real summer, but being the first study on the effects of summer break on the achievement of students with autism, it is important to this literature review. The conclusion that more support is required for children who are more handicapped cannot be drawn from one student in one study, but it is suggestive. Handleman and Harris' study is the only research on the impact of summer break on students with special needs in this literature review that was not conducted in the United States, as it was conducted in Australia.

In summary, the research on the summer regression of students with special needs has demonstrated that students with special needs regress more than the regular population. Both math regression (Allinder & Eicher, 1994; Cortez & Hotard, 1984; Shaw, 1982) and no change in math (Allinder & Fuchs, 1991) were found over the summer. Both reading regression (Allinder & Eicher, 1994; Cornelius & Semmel, 1982; DeVito & Long, 1977; Shaw, 1982) and no change in reading (Beatty, 1985; Cortez & Hotard, 1984; Franklin, 1987) were found over the summer. Regression was also found in other areas of special education such as adaptive skills and behaviour (Allen, 1984; Menousek, 1983; Wilkins, 1983). Regression was found in all areas studied in the four studies on severely developmentally delayed students (Allen, 1984;

Handleman & Harris, 1984; Menousek, 1983; Wilkins, 1983). See Appendix B for a summary of articles on the summer regression of students with special needs.

1.2.5 Fall Recoupment

An important aspect of summer regression research is recoupment. If students regress over the summer, but recoup the losses quickly in September, then regression becomes much less of an issue for policy makers. Only one study was found to research recoupment of students in the general population since 1975 (Grenier, 1975). The rest of the recoupment research has been on students with special needs.

Grenier (1975) administered fall mathematics testing to four separate groups of approximately 200 grade seven students at two-week intervals beginning in late August. This allowed her to examine how long it took for students to recoup any summer losses. The Comprehensive Tests of Basic Skills-Arithmetic and the mathematics scales of the National Longitudinal Study of Mathematical Abilities were used for testing in May and at each of the four times in the fall. Grenier found significant summer losses in math computation, but they were recouped two weeks after the first testing.

Menousek (1983) found that special education students who had returned to May performance levels by October had a higher mean Adaptive Behaviour Scale score than students who had not returned to May levels by October, showing that higher overall prior functioning contributes to recoupment. This is important to this literature review because of the lack of recoupment research in the regular population and because of the population of the current study.

Wilkins (1983) found that moderately to severely handicapped subjects who had parents trained for 12-month service delivery, although they regressed, showed a larger percentage of recoupment by the end of the first six weeks back to school when compared to the control group and to themselves over the previous summer with no intervention. Some subjects with the parent training even experienced some gains in the first six weeks.

Allen (1984) looked at 45 severely multiple handicapped students who attended a summer program and 13 students who did not and thus experienced a 12-week summer break. Of the

students who regressed from not having summer programming, 77% did not recoup losses during the first 40 days of school, and 23% did recoup losses during this time.

Allinder and Eicher (1994) included recoupment data in their research because if students with mild disabilities regressed over the summer break, but recouped their skills within two weeks of school starting in the fall, then reviewing would be sufficient for these students. On the other hand, if recoupment took longer, summer programming may be required. Students recouped losses in reading and math, and significantly improved their reading within the six weeks before the recoupment post-test. Differences in regression between reading and mathematics were not found, but differences in these areas in recoupment were.

Waugh, Fredrick, and Alberto (2009) looked at the recoupment of sound and blending skills of two moderately intellectually disabled students who regressed over the summer in a single-subject design study. After the summer, students both reduced and increased the number of session required to reach the criteria in different areas.

Recoupment times are reported to take anywhere from two weeks to over eight weeks for students with special needs (Allen, 1984; Allinder & Eicher, 1994; Menouskey, 1983; Waugh, Fredrick, & Alberto, 2009; Wilkins, 1983) but only two weeks for students in the general population in the one study found to assess this recoupment (Grenier, 1975).

1.2.6 Assessment Issues with Summer Effect Research

Cooper et al. (1996), as well as some of the researchers who used data from the Sustaining Effects Study reviewed in Cooper et al. (Klibanoff & Haggart, 1981; Heyns, 1987), commented on the problem of the length of the testing interval. In the Sustaining Effects Study, the spring pre-test was five weeks before the end of the school year, and the fall post-test was three to four weeks into the following school year (Heyns, 1987). Therefore, testing intervals include eight to nine weeks of in-school programming time. This programming time may have distorted the results to show more progress in the summer break than actually occurred. This effect could have made a summer absolute loss look like an absolute gain if the gains during the five weeks in the spring and the three to four weeks in the fall were larger than the losses experienced in the summer. Heyns claimed that, based on the data from the Sustaining Effects Study, she found no

absolute achievement loss existed for students over the summer, but she also agreed with Kilbanoff and Haggart's claim that there was evidence of summer losses in mathematics, although mainly in the higher grades. This was determined because if it was assumed that learning during the school year was linear and extrapolated to the end and beginning of the school year, losses would have been found over the summer in this area. This testing interval problem is the main complaint about the Sustaining Effects Study.

One of the main concerns with summer regression research was whether the change in score from spring to fall was absolute or relative. An absolute change, according to Cooper et al. (1996), was the change between two scores on the same test taken twice by the same student and calculating the change in score. This gave the absolute change of a student, showing absolute regression or progress, but it did not explain how the child did compared to other students. Cooper et al. defined relative change as a change relative to a comparison group. The student was compared to a normative sample. The results showed if a student regressed or progressed compared to the comparison or normative sample group, not to themselves. As a result, a negative relative score or change from pre-test to post-test could have indicated either an absolute loss or a smaller gain than the norming sample. This comparison group could have also been the control group in the study, or the students from a special group, such as low SES students, could have been compared to a comparison group. Allinder (1993) compared raw scores to z scores for measuring regression of students with special needs over the summer. Raw scores would be absolute while standard z scores are relative. Raw scores showed regression while z scores did not in the study. She argued that raw scores showed more variation, but z scores showed differences compared to a comparison group.

The use of norm-referenced tests to test progress or regression over the summer was also questioned by Cooper et al. (2006). Cooper et al. found that the effects between spring and fall should have been considered by the normed tests. If they were, and students in the norming population regressed over the summer, then students who plateaued over the summer would have shown progress compared to the norm. If the norming population was only tested a few times of the year with the results extrapolated as linear learning growth over the year, then the test would expect growth over the summer even if the norming population did not progress because of this extrapolation. In this case, if the norming population actually plateaued, and a student taking the

test plateaued, the results would show a loss even though the student progressed just like the norming population.

This could be an argument for criterion-referenced testing, but Allinder and colleagues did not consider standardized norm-referenced or criterion-referenced tests appropriate for testing progress or regression over the summer (Allinder, 1993; Allinder & Fuchs, 1994). They claimed that what was taught and what was tested did not fully overlap, that the tests should not have been used frequently enough to test progress or regression close together, that the tests were designed to measure individual differences, that the tests may not have been sensitive enough to measure these changes because of pretest-posttest score instability, and that the tests assessed too many skills across the curriculum instead of multiple skills at the students' level. They suggested curriculum-based measurement, which is a criterion-referenced test based on the students' curriculum. The test would be more specific to what the students were actually taught and practised.

There are many concerns with the testing and measurement used in some of the summer regression research and these concerns are only exacerbated when research deals with the summer effect on students with special needs. Students with severe disabilities may always be regressing relative to the norm if they learn more slowly, making norm-referenced test less useful, and testing devices that are not sensitive to their rate of learning may minimize gains or maximize losses.

Although there has been research on special needs summer regression, more must be done on students with specific and severe needs, such as autism. This research is more difficult to perform because pre-tests and post-tests must be geared to each individual student and be very specific to show small changes in growth. Because more individual work may be involved in working with students with special needs, fewer students can be assessed in a study with the same resources and manpower, and fewer areas of learning can be covered in each study.

1.2.7 Summary

Cooper et al. (1996) found that students at worst lost one month of grade-level equivalent skills relative to national norms, or one tenth of a standard deviation. They also found that summer

break had a larger negative effect on mathematics computation and spelling than on any other subject area (Cooper et al., 1996), and that there was a small significant positive effect in areas such as mathematics application and vocabulary (Cooper et al., 1996). Cooper et al. suggested that the differences in the effects of summer break on different areas could be related to some skills being practised in the home, or to some subjects requiring factual knowledge and others requiring conceptual understanding.

Other research on the effects of summer break on the achievement of students in the general population found gains, losses, and no change. In reading, gains (Helf et al., 2008, Phillips & Chin, 2004,), losses (Borman et al., 2009; Borman & Dowling, 2006; Borman & Overman, 2005; Haymon, 2009; Johnston et al., 2015; Kim & White, 2008; Schacter & Jo, 2005; Zvoch, 2009), and no changes (Borman et al., 2001; Borman et al., 2004; Kim & Guryan, 2010), were found. Gains were found for high-achieving students in reading (Rambo-Hernandez & McCoach, 2015). In math, gains (Burkam et al., 2004; Downey et al., 2004; Phillips & Chin, 2004) and losses (Bianco-Sheldon, 2007) were found. Cooper et al. (2006) and others (Burkam et al, 2004; Cooper et al., 1996; Downey et al, 2004; Phillips and Chin, 2004) suggested that some of the gains found could be the result of the testing interval including some in-school teaching time. When only low socio-economic status students were considered, losses were found in both reading (Burkam et al., 2004; McCoach et al., 2006) and math (Alexander et al., 2001). Cooper et al. suggested that children from lower-socio economic status families had fewer learning opportunities in reading than middle socio-economic status students.

Research on the effects of summer break on the achievement of students with special needs has demonstrated that students with special needs regress more than the regular population. In math, research found losses (Allinder & Eicher, 1994; Cortex & Hotard, 1984; Shaw, 1982) and no changes (Allinder & Fuchs, 1991). In reading, losses (Allinder & Eicher, 1994; Cornelius & Semmel, 1982; DeVito & Long, 1977; Shaw, 1982) and no changes (Beatty, 1985; Cortex & Hotard, 1984; Franklin, 1987) were found as well. Losses were also found in other areas of special education, such as adaptive skills and behaviour (Allen, 1984; Menousek, 1983; Wilkins, 1983).

Recoupment was found to take two weeks in the regular population (Grenier, 1975).

Recoupment for students with special needs was reported to take anywhere from two weeks to over eight weeks (Allen, 1984; Allinder & Eicher, 1994; Beatty, 1985; Menouskey, 1983; Waugh, Fredrick, & Alberto, 2009; Wilkins, 1983).

This review of the literature suggests that students with special needs regress more consistently than students in the general population. It also suggests that students with special needs take longer to recoup the lost skills in the fall. More research must be done on the effects of summer break on students with special needs (such as autism), looking at specific needs and specific areas of achievement and other areas of impact so that the limited summer resources that are currently provided can be directed at making the largest impact on summer regression possible.

1.3 The Impact of a Child with Autism on Parents

This review of the literature on the effects of a child with autism on the family began with a search for articles with “autism,” “family,” and effects such as “stress” in the titles. The Educational Resources Information Centre (ERIC), Sociological Abstracts, and Psyc INFO databases were searched for articles since 2003 until the present with these terms.

Bibliographies of significant articles were searched. Previous reviews of the literature were also looked for. Articles that were about dealing with the initial diagnosis of autism, adult children with autism, coping strategies, or the effects of external factors on parent stress such as parent traits were not included. Articles on the variety of Pervasive Developmental Disorders were included, as Mungo, Ruta, D'Arrigo and Mazzone (2007) found no statistically significant difference between parents of children with autistic disorder, high functioning autism or Asperger syndrome, and pervasive developmental disorder – not otherwise specified. Only articles available in English were included. When sorting the research, both stress and distress were considered stress for the purposes of this literature review. The purpose of this review was to understand the effects a child with autism has on parents that may be exaggerated during the summer break because there is no break provided by school from the child's behaviours and other symptoms during the day.

Parents of children on the autism spectrum had more depression (Benson, 2006; Ingersoll & Hambrick, 2011), anxiety (Bitsika & Sharpley, 2004; Lee, 2009), daily hassles (Quintero & McIntyre, 2010), and hopelessness (Pisula, 2003) than parents of children without disabilities.

Parents of children on the autism spectrum also displayed less family adaptability and cohesion (Higgins, Bailey, & Pearce, 2005), relationship satisfaction (Brobst, Clopton, & Hendrick, 2009), sleep quality and quantity (Meltzer, 2008), quality of life (Lee et al., 2009), physical activity and health (Mungo, Ruta, D'Arrigo, & Mazzone, 2007), social relationships (Mungo et al., 2007), and sense of coherence, or confidence that a situation is manageable and engagement is meaningful (Pisula & Kossakowska, 2010) than parents of children without disabilities.

Mothers of children on the autism spectrum had more depression (Abbeduto et al., 2004), more emotional disorder (Totsika et al., 2011), more fatigue (Smith et al., 2010), more negative emotions (Smith et al., 2010), and lower sense of self-efficacy (Meirsschaut, Roeyers, & Warreyn, 2010) than mothers with typically developing children. Mothers of children with autism had less positive perceptions of their child than mothers of children with other disabilities (Griffith, Hastings, Nash, & Hill, 2010). Mothers of children with autism also experienced more depression (Hastings et al., 2005), more anxiety (Hastings, 2003), and poorer health related to quality of life (Allik, Larsson, & Smedje, 2006) than fathers of children with autism.

1.3.1 Stress

The National Research Council (2001) stated that the parents of children with autism may experience sadness, anger, or disappointment about their child's disability and how it affects their lives, and that although many families cope well, some experience “very substantial stress.” Thirty-eight percent of parents of high functioning children with autism showed a clinically significant total stress score on the Parenting Stress Index – short form (Bundy & Kunc, 2009). Myers, MacKintosh, and Goin-Kochel's (2009) found that stress was the most frequent theme in parents' accounts of how their child with autism affected them and their families. Similarly, Hutton and Caron (2005) found that the overwhelming majority of parents used the word 'stressful' to describe having a child with autism.

Pisula (2003) reviewed the literature from the 1990's on parents of children with autism, including parental stress and the perception of the child. She found that parents of children with autism experience more stress as compared to parents of children with other disorders. This effect has been shown to be more prominent in mothers, as opposed to fathers. In fact, mothers of children with autism had more stress than even mothers of children with chronic physical

illnesses. Not only did parents of children with autism experience more stress, this stress was connected with personality characteristics and behaviour of the child with autism (Pisula, 2003). The child's stereotypic behaviour, self-stimulation, and destructive behaviours caused this stress.

Research has continued to show that parents of children on the autism spectrum have more stress than parents of children without disabilities (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). Also, parents of children on the autism spectrum also had more stress than parents of children with Down syndrome (Griffith, Hastings, Nash, & Hill, 2010; Pisula, 2007).

Research that specifically looked at mothers, as opposed to fathers, found that mothers of children on the autism spectrum have more stress than mothers with typically developing children (Duarte, Bordin, Yazigi, & Mooney, 2005; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Meirsschaut, Roeyers, & Warreyn, 2010) and with other developmental disabilities without autism (Estes et al.; 2009). Smith et al. (2010) found that mothers of children with autism had more stressful daily events than mothers with typically developing children. Yamada et al. (2007) found that although mothers of children with PDD had more stress than parents of typically developing children, fathers of these children did not. Mothers of children with autism were found to experience more stress than fathers of children with autism (Dabrowska & Pisula, 2010). In their meta-analysis on stress of parents of children with and without autism, Hayes and Watson (2012) claimed that research is unclear about differences between mothers and fathers because most research is on mothers only or mothers and fathers without differentiating between them. Foody, James and Leader (2015) found that mothers reported higher parenting responsibility, distress, anxiety, and depression than fathers, but that fathers had higher blood pressure and heart rate variability, both physical signs of stress.

1.3.2 Effects of Child Variables on Parent Stress

Child variables that influenced the level of stress that parents of children with autism had included the child's autism symptom severity, adaptive skills, and problem behaviours. Developmental functioning level, or level of intellectual disability, did not demonstrate a significant effect on stress (Bundy & Kunc, 2009; Herring et al., 2006). High intellectual functioning did not compensate for behaviour problems in children with autism (Rao & Beidel, 2009).

The child's autism symptom severity was found to have a direct effect on stress (Ingersoll & Hambrick, 2011; Yamada et al., 2007) and maternal stress (Ekas & Whitman, 2010; Hoffman et al., 2008), although Baker-Ericzen et al. (2005) only found this effect for the social interaction subtest of the Gilliam Autism Rating Scale. Autism symptom severity was found not to impact maternal stress (Hastings et al., 2005) or stress (Phelps, McCammon, Wuensch, & Golden, 2009; Phetrasuwan & Miles, 2009) in other studies. This discrepancy could have been partially due to many of the studies showing a relationship between autism symptom severity and parent stress using diagnostic tests that have sub-tests on problem behaviours, such as the Autism Behaviour Checklist and the Autism Severity Index. It could have been that the severity of problem behaviour symptoms causes stress, while other autism symptoms are not as significant.

Although Hastings et al. (2005) found that adaptive skills did not have a significant effect on maternal stress, other studies found that adaptive behaviours such as communication, social, life/self-help, and motor skills did have a significant effect on stress (Hall & Graff, 2011; Lecavalier, Leone, & Wiltz, 2006) and maternal stress (Tomanik, Harris, & Hawkins, 2004), although Lecavalier et al. (2006) only found the effect for social and communication skills. Papagergiou and Kalyva (2010) found in qualitative interviews that communication was the most important problem faced by parents of children with autism.

Lecavalier et al. (2006) found that behaviour problems were more associated with stress than child adaptive behaviour or parent familiarity with applied behaviour analysis (a method of teaching children with autism) and autism spectrum disorders. Herring et al. (2006) found that child emotional and behaviour problems contributed more to maternal stress than diagnosis or delay. A child's behaviour or emotional problems have an effect on maternal stress (Bromley, Hare, Davison, & Emerson, 2004; Estes et al., 2009; Hastings, 2003) and stress (Phetrasuwan & Miles, 2009; Rao & Beidel, 2009). A qualitative study found that “the parents [of children with autism] who were the most distressed were those whose children were aggressive and/or severely obsessive (Gray, 2002). Ninety percent of parents reported that they were sometimes unable to deal effectively with their child's behaviour, and felt stretched beyond their limits (Bitsika & Sharpley, 2004). Of the most commonly coded sources of stress for parents of children with autism in the qualitative research, behavioural issues were the most cited and one of the few that were based on child characteristics (Hall & Graft, 2010; Myers, MacKintosh, & Goin-Kochel,

2009; Papagergiou & Kalyva, 2010).

Two more recent studies looked at multiple child variables in the same study. McStay, Trembath, and Dissanayake (2014) found that child behaviour problems impacted maternal outcomes more than any other child characteristic. Brei, Schwarz, and Klein-Tasman (2015) found that child behaviour problems accounted for most of the variance in parent stress. Giovagnoli et al. (2015) found that behavioural and emotional problems are strong predictors of parent stress, and found no associations with severity of autism.

1.3.3 Effects of Support on Parent Stress

When toddler aged children with autism received childcare interventions, mothers showed significant reductions in child-related stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). Also, when a grown child with autism moved out of the family home, maternal anxiety was reduced (Barker et al., 2011). These two results suggest that when there is support in the form of care for the person with autism, stress and anxiety is reduced in the parents. An increase in family, social, emotional, and informal support was found to lead to decreased maternal stress (Ekas, Lickenbrock, & Whitman, 2010) and less maternal psychological distress (Bromley, Hare, Davison, & Emerson, 2011), as well as an overall better daily mood (Pottie, Cohen, & Ingram, 2009). Hutton and Caron (2005) found that most parents said services greatly reduced their stress, although some found them more stressful due to the work involved. Norton and Drew (1994) noted that respite care is crucial for the well-being of parents of children with autism. Hall and Graff (2011) found an association between parent stress and the need for additional family support. Meadan, Halle, and Ebata (2010) claimed that although there is limited research on the effect of respite care on families of children with autism, they believe that respite would reduce stress caused by issues such as time demands. Time pressure on mothers contributed to maternal mental health problems (Sawyer et al., 2010). Both parental cognitions and socioeconomic support were found to be more significant predictors of parental mental health than even child-centric variables, such as behaviour (Falk, Norris, & Quinn, 2014).

Sharpley and Bitsika (1997) found that parent well-being was affected by the knowledge and understanding about autism and their child that supporting family members were perceived to have. These facts demonstrate that when parents have relief, stress levels go down, and that the

quality of this care could be relevant. This is significant, because in the summer, relief for students with autism typically goes down. In addition, in qualitative focus group interviews by Hall and Graff (2010), several participants found an extended school year or summer school to be challenging. Participants described how summer staff were unprepared to provide the services that school staff provided during the regular school year.

1.3.4 Siblings

In 2010, three literature reviews on the effect of a child with autism on their siblings were published in journals from three different disciplines (disability studies, social work, and nursing). Meadan, Stoner, and Angell (2010) found that the literature on the effects of a child with autism on their siblings has mixed results. They found positive effects such as higher levels of self-concept and higher levels of social competence, no effects, and negative effects such as low levels of pro-social behaviour, increased internalizing and externalizing problem behaviour, feelings of loneliness, and delays in the acquisition of social skills. Ferraioli and Harris (2010) showed similar findings, such as enhanced self-concept, no adjustment differences, and negative outcomes such as poor adjustment and increased risk for internalizing behaviour such as depression and anxiety. They also found that siblings may be fearful of their sibling with autism, embarrassed by their sibling, worried about their sibling's future, or stressed about aggression or take on a care-taker or protector role. Finally, Smith and Elder (2010) also seem to have found mixed results; siblings of people with ASD have similar behaviours to siblings of people with other disabilities, but siblings are influenced by the context of their families and need support interventions.

Many other studies were done in 2009 and 2010 that were not included in these reviews. Orsmond, Kuo, and Seltzer (2009) found that adolescents engaged in more shared activities and reported more positive affect in their sibling relationship when their sibling with ASD had fewer behaviour problems. Petalas, Hastings, Nash, Lloyd, and Dowey (2009) found that when they looked at siblings of children with intellectual delays with and without autism to separate the effects of intellectual delays from autism, siblings of children with autism and intellectual delays had more emotional problems than siblings of children with intellectual delays only as well as normative data. Barak-Levy, Goldstein, and Weinstock (2010) found that siblings of children

with ASD who are expected to be helpful feel responsible for their sibling and find this distressing. The siblings also have much lower participation in child activities and poorer social relations and school performance. Petalas et al. (2009) found that there were both positive and negative aspects of having a sibling with ASD, but siblings focussed on social isolation, aggressive behaviours, and reduced recreational time. Quintero and McIntyre (2010) found no significant difference in the social, behavioural, or academic adjustment of siblings of children with and without autism.

1.3.5 Positive Effects

There was some research that found positive effects of having a child with autism, in spite of the difficulties. Phelps, McCammon, Wuensch, and Golden (2009) found that although stress was higher than enrichment for parents of children with autism, parents still found enrichment in their experiences, as reported on the Effects of the Situation Questionnaire. The greatest enrichment occurred in the areas of emotional well-being, parents' views of themselves, and religious or spiritual life. Altieri and Von Kluge (2009) found that nearly all parents interviewed found a positive learning experience, and that many of the parents claimed that their lives were better because they were more patient, more compassionate, more humble, and more accepting. They also claimed finding true friendships, strengthened marriages and families, and increased spirituality. They called the experience "priceless". Phelps et al. (2009) found that 20 of the 80 respondents to their questionnaire reported benefits to having a child with autism such as greater selflessness, more compassion, and a feeling of peace during uncertain times. Parents of children with autism who published their narratives online saw themselves as "daring mountain climbers" instead of victims (Fleischmann, 2004). Myers, Mackintosh, and Goin-Kochel (2009) found that although nearly half of all parents surveyed gave completely negative responses to a question about how their child with autism affected their lives and their family's life, 1 in 10 parents gave completely positive responses to the question. These parents discussed how the child made them a better person and how they appreciate the unusual aspects of their child. Hastings et al. (2005) found that mothers had more positive perceptions of their child than fathers.

1.3.6 Stress Theory and Parents of Children with Autism

Hill was called “the father of family stress theory”, and he developed the ABCX formula of family stress (Gauthier Weber, 2011). This formula forms the basis of most contemporary family stress models, including the often used Double ABCX Model (Gauthier Weber, 2011). Hill's ABCX Model uses three factors, factors a, b, and c, to produce the outcome, x. Factor a is the stressor event, factor b is the family's resources, and factor c is the definition the family makes of the stressor event (Malia, 2006). McCubbin and Patterson's Double ABCX Model took the pileup of stressor events into account (Malia, 2006). The Double ABCX Model has three pre-crisis dynamic, a, b, and c, which produce the crisis phase, x. The a is the stressor, the b is the existing resources, and the c is the perception of the stressor. (Malia, 2006). There are then the post-crisis variables of aA, bB, and cC, which lead to xX, or adaption, represented in the model by a pair of letters, one lower case, one upper case. aA is the pileup of stressor on top of the initial stressor, bB is the existing and new resources, and cC is the perception of the stressor, pileup, and resources (Gauthier Weber, 2011).

Research in family stress in families with children with autism often uses the Double ABCX Model of Family Adaption (Manning, Wainwright, & Bennett, 2011; Paynter, Riley, Beamish, Davis, & Milford, 2013; Pozo & Sarria, 2014; Ramisch, 2012) or a modified Double ABCX Model (Bristol, 1987). Perry's “Model of stress in families of children with DD” (2004) was developed in response to the limitations of the ABCX Model and the Double ABCX Model. Perry's model includes stressors, resources, supports, and outcomes. The stressors are child characteristics and other life stressors. The resources are individual's personal resources and family system resources. The supports are informal social support and formal supports and services. The outcomes are negative parental outcomes and positive parental outcomes. Bluth, Roberson, Billen, and Sams (2013) base their “Parents of Children with ASD Stress Model” on Perry's model. Bluth et al. (2013) claim that Perry intended for her model to include families of children with all developmental disabilities, but they found the model too simple for autism. They found that families of children with autism experience a greater level of stress and require a model tailored to them and their unique experiences. Bluth et al. (2013) have the same four areas, but add maternal and paternal perceptions of child characteristics to stressors and

parenting couple resources to resources. They change the outcomes to mother outcomes, father outcomes, and a combined parenting couple outcomes.

Both Perry (2004) and Bluth et al. (2013) agreed that social supports are the main support for children with developmental disabilities, including autism. Bluth et al. believed that the failure of social networks, or informal social supports, to consistently provide support to families of children with autism is because of the social unacceptability of some of the characteristics of autism. This would put even more weight on formal social supports. Perry claimed that formal social supports include professional or paraprofessional interventions, including education/treatment programs, as well as respite care. The importance of formal social supports, including education, is relevant to the current research because in the summer this support is greatly reduced.

1.3.7 Summary

Parents of children with autism experience more stress and other negative effects than parents of children without disabilities and with other disabilities, but they also experience some positive effects. Research has found that child variables that influence parent stress include autism symptom severity, adaptive skills, and problem behaviour. Research has also found that support, especially quality support in the form of care for the person with autism, reduces parent stress.

1.4 Rationale for the Current Study and Research Questions

The purpose of this research was to investigate the effect of summer break on the academic, social, life, communication, and behaviour skills of elementary children with severe autism and to assess the recoupment of skills in the fall. The evidence to date has suggested that summer break has a negative effect on students with special education needs (Shaw, 1982) and that students with special education needs recoup skills lost over the summer more slowly than students in the regular program (Menousek, 1983). Based on the review of the literature on the effect of summer break on student achievement, it was hypothesized that students with severe autism would regress in academic, social, life, communication, and behaviour skills, and would require over one month to recoup these skills. One month has been chosen as the recoupment measurement time because recoupment that takes longer than one month would demonstrate no

learning for 3 months, or a quarter of the year. If students with autism regress over the summer break, and recoupment requires a significant amount of time in the fall, then the learning of students with autism is greatly negatively affected. This research expands the current literature because the previous research on summer effect either did not use children with severe autism, or only assessed them in one small area (labelling picture cards).

The secondary purpose of this research was to assess the impact of summer break on the stress of parents of children with severe autism and to gain a qualitative understanding of the impact on parents. The research on the stress of parents of children with autism suggests that they experience more stress than most other parents. Child variables that influence the level of stress of parents of children with autism include the child's autism symptom severity, adaptive skills, and problem behaviours. Also, when there is support in the form of care for the person with autism, parent stress is reduced. Based on the review of the literature on the impact of a child with autism on parents, it was hypothesized that parents would feel more stress during the summer break than they do during the school year. Since the first hypothesis was that behaviours would rise during the summer break, and the literature review found that behaviour is the main child characteristic that influences parent stress, parents will enumerate behaviour as a source of this stress. Parents of children with autism already experience a great deal of stress, and if summer break, through dealing with child regression in areas that influence parent stress or lacking care support for the child with autism, increases this stress, then families of children with severe autism may require more assistance over this break to reduce their levels of stress. This research expands the current literature because the effect of summer break, when there is little programming and less qualified relief, has not been studied as a source of stress for parents of children with autism.

In summary, the research hypotheses states that students with severe autism will regress in academic, social, life, communication, and behaviour skills over the summer break and they will require over one month to recoup these skills in the fall. Also, parents of students with severe autism will feel more stress during the summer break than they do during the school year and they will enumerate behaviour as a source of this stress. In addition to the research hypothesis, this study aims to find a qualitative understanding of the impact of summer break on children with severe autism and their parents.

Method

2.1 Subjects

The participants were ten children identified with autism by their Identification, Placement, and Review Committee and recognized as severely autistic by their teachers and parents due to their behaviours, needs, and lack of integration in the regular system. The children were of elementary school age, or between the ages of four and 13 at the beginning of data collection. All but one participant were male. They were working towards Individual Education Plan (IEP) goals from the Assessment of Basic Language and Learning Skills (ABLLS). They were all in a full time school program with an individual education plan. Children were excluded if they were in an Intensive Behaviour Intervention program, as their programming continued into the summer, and the purpose of this research was to study the effects of summer break on students with severe autism. Intensive Behaviour Intervention involves year-round programming, and can be full time in the place of school, or part time alongside of a school education. It was the mother of each child who identified as the primary caregiver, and two fathers who were the partners of two of the mothers, who participated in part of the interviews.

Participants were selected using convenience sampling due to the low incidence of severe autism and for ease of access to children and families. A list of elementary schools with autism classrooms in Greater Sudbury, Ontario that included the number of autism classrooms in each school was obtained from the Rainbow District School Board's autism consultant. The researcher started by sending letters (see Appendix C) to the two schools with the most autism classrooms asking for their participation. Once consent was received from principals, letters were sent to teachers. Schools and teachers were contacted first because some of the testing was performed in the classroom, so school and teacher support was required. Once teachers of students who qualified for the study agreed to participate, letters were sent home with students in their classrooms who qualified for the study. The school was asked to telephone the families to tell them about the letter within a couple days of sending it home. The letters detailed the purpose of the interviews and assessments, the commitment required, and the eligibility and

exclusion criteria. They included that participation was voluntary, their right to withdraw at any time, their right to review and withhold interview information, and confidentiality.

Confidentiality was maintained by using pseudonyms, locks, and computer passwords. Further schools were contacted based on number of autism classrooms, until ten participants had been secured. In total, six schools in Greater Sudbury were contacted, including 15 autism classrooms. Of the 15 classrooms, six had no qualifying students (due either to the severity or the academic level of the classroom population), one had no willing participant families, two teachers declined participation, one teacher did not reply, and five classrooms had at least one participant family. Ten students from five classrooms in four schools in the Rainbow District School Board in Greater Sudbury were included in the study, including the researcher's own classroom. Ten was chosen as the number of participants so that all of the interviews and assessments could be done as close to the end of the school year and the beginning of the following school year as possible by one researcher.

Informed consent (assent) was acquired from the child at each meeting with them at the school, by gathering data about how the student refuses from parents and observing the child for this behaviour. (For example, some children scream to avoid a person or task, while others scream as self-stimulatory behaviour, so this data was collected about each child before meeting with them.) All children were at the least interested and at the most excited about working with the researcher. Reinforcement data was also collected, and the children were encouraged to cooperate using one of their high reinforcers. (For example, if a child liked gummies, the child received a gummy after every few responses.)

2.2 Bias

The principal author of this study has taught children with severe autism since 2005. She is employed at the board that is involved in this research, and was teaching three of the participants at the time of this study. Although she recognizes that this may lead to bias during both the data collection and analysis of the data, she feels that the benefits of having a researcher who has some understanding of the abilities and difficulties of the participants outweighs the chance of bias, and that bias can be greatly reduced with some effort. Efforts made to reduce the effect of bias during data collection included using another interviewer for participants known to the

researcher, avoiding prompting during assessment, and taking notes about the process during interviews. Bias during data analysis was reduced by having participants member-check the final codes by hearing the codes and sample quotes used in the codes and giving feedback to the researcher about them, using tools such as “include synonym” in the NVivo qualitative analysis software to code interviews, and by making notes about the process during the coding of the interviews to ensure that codes were fully based on interviews and not the pre-conceived notions of the researcher.

2.3 Measures

Demographic, qualitative, and quantitative measures used in this research will be discussed in this section.

2.3.1 Demographic Information

Basic descriptive information was gathered from the parents, including school placement of the child (intensive support class, self-contained school, integration), parents' marital status, family economic class, parent status (natural or adoptive, foster), number of siblings, siblings with autism, and formally diagnosed severity. At the end of the summer, hours of summer programming (relief, summer programs, programs run by parents), if any, were added to the data sheet.

2.3.2 Assessment of Basic Language and Learning Skills

The Assessment of Basic Language and Learning Skills – Revised (ABLLS) (Partington, 2006) is divided into four skills assessment areas: basic learner skills, academic skills, self-help skills, and motor skills. These areas are further divided into 25 skills area subsets. Each of the 25 skills areas include a variety of tasks that are scored out of a total of one to four with criteria for each level. (That is, some tasks are scored out of one if it is just a yes/no for whether or not they have the skill, while other tasks are task analysed for the various steps, such as the steps in tying shoes, or percentage of the task accomplished, such as counting to a certain number.) Basic learner skills include cooperation and reinforcer effectiveness, visual performance, receptive language, imitation, vocal imitation, requests, labelling, intraverbals, spontaneous vocalizations,

syntax and grammar, play and leisure, social interaction, group instruction, follow classroom routines, and generalized responding. Academic skills include reading, math, writing, and spelling. The self-help skills include dressing, eating, grooming, and toileting, and the fine and gross are the motor skills. An example of a task in the reading skills area (one of the academic areas that are used in this research) is task Q5, “match words with pictures”. A score of one is given if a student can match two words to pictures, two is given for five words, three is given for ten words, and four (the highest score), is given for 20 or more words.

The ABLLS has high inter-rater reliability ($r=.97$ for the total score, $.90$ for reading and $.82$ for math). The ABLLS has concurrent validity with significant correlations between the ABLLS (percentage of skills acquired) and the Vineland Adaptive Behaviour Scale (composite $r=.49$) and the Mullen Scales of Early Learning (IQ estimates $r=.57$ and mental age estimates $r=.90$). Although all skill areas correlated, there was greater correlation between areas that measured the same skill (Sullivan, 2010). The ABLLS does not have other psychometric data associated with it because it is designed to be a curriculum and assessment tool to be used daily for program planning and assessment in the classroom/therapy centre, not a psychometric test.

Only chosen ABLLS goals in each child’s IEP were used in this research. The purpose of the use of goals in the IEP was to assess skills that the students were working on, so the entire ABLLS was not used. Because each child had different goals, percentages of correct responses were used. The percentage of each goal was used to obtain a score that was unweighted, and the percentage of all goals added together was used to obtain a weighted score. Let’s use an example of a student with goals to read 12 words, label 26 letters, match 10 numbers to amounts, and count to 30 who got the following scores at the first assessment: 8/12, 13/26, 8/10, 21/30. To calculate an unweighted score, giving each goal equal weight, the percentages of each goal (67%, 50%, 80%, 70%) was averaged to get 66.7%. To calculate a weighted score to give goals with more tasks in them more weight, the scores were first added (50/78), then converted to a percentage of 64.1%.

2.3.3 Vineland Adaptive Behaviour Scales

Adaptive behaviour is defined as the performance, not just ability, of daily activities required for personal and social sufficiency (Sparrows, Cicchetti & Balla, 2005). The Vineland Adaptive

Behaviour Scales (VABS) is designed for people from birth to 90 years old. The parent/caregiver rating form takes 30 to 60 minutes to complete. It looks at adaptive behaviour in the major domains of communication, daily living, socialization, motor skills (up to seven years old), and optional maladaptive behaviour. The major domains are divided into sub-domains, communications being divided into receptive communication, expressive communication, and written communication; daily living being divided into personal daily living skills, domestic daily living skills, and community daily living skills; socialization being divided into interpersonal relationships, play and leisure skills, and coping skills; motor skills being divided into gross motor skills and fine motor skills; and behaviour being divided into internalizing behaviours, externalizing behaviours, and other behaviours. The motor skills domain was not used in this study due to the limitations in age. Example statements range from “Turns eyes and head toward sound” to “Listens to an informational talk for at least 30 minutes” in the listening and understanding sub-domain. The rating scale respondent replies with the statements usually, sometimes or partially, never, or don’t know. Example behaviour statements include “Sucks thumb or fingers and “Engages in inappropriate sexual behaviour (for example, exposes self, masturbates in public, makes improper sexual advances, etc.)”. The respondent replies with often, sometimes, or never and for part two also with severe or moderate. One of the advantages of the VABS for a researcher is that the child being assessed does not have to be present. Assessment can be made when items cannot be measured through direct administration by using the assessor’s historical knowledge of the examinee. The VABS can be used for progress monitoring to assess treatments, and in the current study the treatment is summer break.

The VABS is normed with over 3000 subjects. Internal consistency reliability correlations range from .77 to .97 across age groups and domains. Test-retest reliability correlations range from .74 to .98 across age groups and domains. Interrater reliability correlations range from .71 to .81 across age groups and domains except for maladaptive behaviours, which range from .39 to .87 (Community-University Partnership for the Study of Children, Youth, and Families, 2011).

Validity is demonstrated by correlations of .69 to .96 with the previous VABS, .70 with the Adaptive Assessment Systems II, and .34 to .74 with the Behaviour Assessment System for Children II (BASC). The focus of the BASC is maladaptive behaviour, while the focus of the VABS is adaptive behaviour (Community-University Partnership for the Study of Children,

Youth, and Families, 2011). When Maladaptive is compared to maladaptive on the BASC, the correlation is .80 for the child parent rating form. The VABS is not related to the Wechsler Intelligence Scales for Children III, with near 0 correlation.

2.3.4 Parenting Stress Index

The Parenting Stress Index – Third Edition (Abidini, 1995) takes parents approximately 20 minutes to complete. The scale is designed for children from one month to 12 years old. The Parenting Stress Index shows parent stress in three domains: child characteristics, parent characteristics, and optional situational/demographic life stress. It consists of 101 items for the child and parent characteristics domain, and 19 items from the optional life stress domain. Child characteristics include the sub-domains of distractibility/hyperactivity, adaptability, demandingness, mood, acceptability, and the reinforcement they give their parents. Parent characteristics include the sub-domains of competence, isolation, attachment, health, role restriction, depression, and spouse. Example true/false statements include, “My child is so active that it exhausts me” and “I enjoy being a parent”. The Parenting Stress Index (PSI) can be used as a pre-post measurement of intervention effectiveness, in this case, summer break being the intervention. The PSI also includes the questionnaire about traumatic life events that could impact stress so that these events can be taken into consideration when analysing data.

The PSI was normed on 2633 mothers. It has internal consistency reliability of .70 to above .90 for the domains and the total stress scale. Test-retest reliability ranged from .55 to .96 for the domains and the total stress score. Validity is demonstrated by a .42 to .66 correlation with the Bayley Scale of Infant and Toddler Development and a .36 to .84 correlation with the Family Impact Questionnaire (Kisker, 2011). According to the manual, parents of children with varied disabilities, including autism, had high levels of stress in the child domain. Parents of children with autism experienced more stress than parents of children with Down's Syndrome. Parents of children with autism and parents of children with externalizing behaviours reported the same level of stress (Abidini, 1995).

2.3.5 Interviews

The in-depth interview method assumes that the people interviewed have specific knowledge

about the social world that can be shared verbally (Gills & Liamputtong, 2009). In his guide for researchers in education and social science, Seidman (2006) claims that the in-depth interview is based on understanding the lived experiences of other people and the meaning they make of that experience. He claims that the purpose of the interview is to have the participant “reconstruct” their experiences by asking them open ended questions and having them build upon their initial responses. Seidman (2006) uses three interviews. This is similar to Gill and Liamputtong (2009), who find that interviewers get more insight from later interviews than earlier ones. Seidman (2006) uses the first interview to establish context of the experience, the second interview to reconstruct details of the experience, and the third interview to reflect on the meaning of the experiences. He suggests 90 minute interviews 3 days to a week apart, but leaves room to adapt these suggestions to various situations. The interviews in this research are based on these methods, but adapted to the participants and subject matter involved.

2.4 Paradigm

To answer the question of the impact of summer break on children with severe autism and their families, an interdisciplinary and mixed methods approach was chosen. Interdisciplinarity means “between fields of study” or “derived from two or more” (Repko, 2008). Repko defines interdisciplinary studies as “a process of answering a question, solving a problem, or addressing a topic that is too broad or complex to be dealt with adequately by a single discipline and draws on disciplinary perspectives and integrates their insights to produce a more comprehensive understanding” (Repko, 2008, 12). The reason the disciplines cannot answer these questions alone is because of increased specialization and increased complexity in society (Thompson Klein, 2010). Interdisciplinary integrates information, data, techniques, tools, perspectives, concepts, and theories from two or more disciplines to solve problems that are difficult to solve through a single discipline (Boix Mansilla, 2010, 289).

The research problem of the impact of summer break from school on children with severe autism and their parents is interdisciplinary, including psychology, education, and disability studies. The various subjects, tools, theories, concepts, and assumptions of these disciplines contribute to the research. Psychology studies the subjects of adaptive behaviour and stress, education studies achievement, and disability studies looks at disabled people and their role in society. Tools from

various disciplines are also used, including the Vineland Adaptive Behaviour Scales and the Parenting Stress Index from Psychology, the Assessment of Basic Language and Learning Skills from Education, and models of disability from disability studies. Theories used in this research include stress theory from psychology and disability theory from disability studies. Concepts used in this research include stress and coping from psychology, regression and recoupment from education, and disability and impairment from disability studies. Assumptions in psychology and education are mainly empirical, with testing of smaller populations applied to larger populations. Disability theory, on the other hand, constructs theories and believes in the social construction of disability.

Similarly, mixed methods research collects and analyses qualitative and quantitative data, and mixes or integrates the two types of data, taking on the strengths of each (Creswell & Plano Clark, 2011). This may or may not overlap with interdisciplinarity, because both types of methods could come from the same discipline, or two disciplines could be combined using the same type of method from each (qualitative or quantitative). Mixed methods research is recommended when one data source may be insufficient, or when one type of evidence may not tell the whole story (Creswell & Plano Clark, 2011). Mixed methods research is also used for methods triangulation (Hesse-Biber, 2010). The results may even be contradictory (Creswell & Plano Clark, 2011). Like interdisciplinarity, mixed methods has moved from mixing two methods to mixing in all stages of research (Creswell & Plano Clark, 2011).

Mixed methods are useful when assessing the effects of summer break on the achievement of students with severe autism who may regress in ways that are not detectable by most assessments, or in ways that may be detectable, but that may have implications for the child and the family beyond the test scores. Both quantitative tests and qualitative interviews will give a clearer, real-world picture of the effect of summer break on student achievement. Mixed methods are also useful for exploring the effect of summer break on the stress of parents of children with autism, when parent stress is already high and may have a complex relationship with other variables. Again, a quantitative stress rating scale combined with interviews about stress will give a clearer picture of how summer impacts parent stress.

Creswell and Plano Clark (2011) suggest using certain world views or paradigms with mixed

methods research. Although they do allow for a mix of two different world views if the qualitative and the quantitative data are collected and analysed in phases, they suggest using one world view that works with both qualitative and quantitative data if data is collected concurrently. They suggest pragmatism as the world view that is best associated with mixed methods research because both qualitative and quantitative research methods may be used, the research question should be the most important aspect of the research, and the “forced-choice dichotomy between postpositivism and constructivism should be abandoned” (p.44).

Pragmatism does not force the use of either postpositivism or constructivism alone.

Postpositivism studies one singular reality based on unbiased, objective data collection deductively, while constructivism looks at multiple perspectives subjectively, inductively, and allowing and discussing bias (Cresswell and Plano Clark, 2011). The ontology of pragmatism uses both a singular reality and multiple perspectives. Its epistemology values both objective and subjective knowledge, and using “what works” from diverse approaches to answer research questions instead of being impartial, objective and unbiased only or subjective, close to the subjects, and discussing bias. The pragmatic approach may combine deductive and inductive thinking (Cresswell & Plano Clark, 2011) instead of using only one.

Pragmatism is important in answering the question of the effect of summer break on students with severe autism and their families, because it is important to gather quantitative, objective, unbiased data to show where regression has actually taken place, but it is also important to see how the families of children with autism experience summer break and make meaning from those experiences. Also, although theories on disability and stress inform the research, the model of how summer break impacts families of children with autism comes directly from the participants in this research, and will be compared to similar existing theories.

2.5 Procedure

Ethics approval was acquired from the university and the school board approached in this research (see Appendix D).

For each participant, the first two skills from the reading area and the first two skills from the math area of the Assessment of Basic Language and Learning Skills – Revised that were on the student's Individual Education Plan (IEP) for the second term of the school year that data

collection began were assessed. If the student did not have two goals in each area, more goals from the other area or other academic goals (eg. printing) or other ABLLS goals in the academic area of the IEP were used. The skills were assessed at four time points to give a baseline, the effect of the summer break, and possible recoupment of lost skills. These time points occurred during the spring approximately two months before the end of the school year, at the end of the school year, two months later at the beginning of the next school year, and a month into the next school year. Assessment occurred in the child's own classroom or work room that they were used to at the school, using the child's learning resources. (For example, if they were learning how to read five words, the words chosen by the student's teacher were used.) Each student had different skills being tested, because each student was at a different part of the ABLLS curriculum and had different goals in their IEP that were being worked on during the school term. The researcher performed the ABLLS testing on the students. Students were not prompted.

In addition to the four assessments in the classroom with the students, four meetings were held in the home with the parents at the same four time points, for a total of eight meetings with each participant family. Consent was collected and parents were asked to create their own and their child's pseudonyms at the first meeting. Demographic information was collected at the first and last home meetings.

The Vineland Adaptive Behaviour Scales was administered at all four home meetings for the purposes of a baseline, the effect of summer break, and possible recoupment of skills to compare skills in communication, life skills, socialization, and problem behaviour.

The Parent Stress Index was administered at the first two home meetings in the spring and at the beginning of summer break to compare stress levels of the parent(s) during the school year and during the summer break. It was not administered at more times because, unlike for academic and adaptive skills, school is not a program designed affect parent stress over time.

The Parent Stress Index and the Vineland Adaptive Rating Scales were to be filled in by the primary caregiver of the child. Parents decided who the primary caregiver of the child was. Parents were given the option to answer the rating scale questions interview style, or to do the scales themselves with the researcher available for questions and to review for basal and ceiling

acquisition. Parents chose a combination of verbally answering and writing. When parents opted to fill in the scales by themselves, a brief instruction sheet was included for them to refer to.

Interviews were performed at the first three home meetings: in the spring, at the end of the school year, and at the beginning of the following school year. One parent delayed the first interview until the second interview time due to personal issues, although she completed the VABS and the PSI so that baseline data could be gathered. Although Seidman (2006) recommends that there be three interviews up to a week apart, he does allow for using alternative spacing as long as a structure of three interviews is maintained so that participants can establish context at the first interview, reconstruct details at the second interview, and reflect at the third interview. The three interviews were one or two months apart to allow for the spacing required by the rating scales and to be sure that interviews were done over both school and summer break so that the full impact of summer could be discussed. Seidman (2006) recommends 90 minute interviews, but what is important to Seidman is that the length of time be decided before the interviewing starts. The interviews lasted 90 minutes including the rating scales and other data collection that took place at the beginning of each meeting. The interviews helped to gain a qualitative understanding of the impact of summer break on children with severe autism and their parents.

Interviews were held in the family home or at a location of their choosing, such as a public library, at a time convenient for both parties. In a situation where parents were not physically available during an interview, telephone interviews were accepted since there were three interview times and this was difficult for families to meet, especially over the summer break when they may travel or go to their cottages. When there were two parents, parents could choose to be interviewed together or separately, or the primary caregiver of the child could complete the interviews independently. All interviews were performed by mothers as primary caregivers, with two fathers participating at the end of interviews at the request of the mother and because the questions interested the couples.

The first interview, during the school year, was performed to record responses given outside of the context of summer break. It was a brief interview after introductions, obtaining informed

consent, descriptive data collection, as well as the first PSI to obtain a stress baseline for during the school year and the first VABS to obtain a baseline of adaptive and behaviour skills. The first interview, based on the approach by Seidman (2006), is an interview about the context of the topic and life history. Questions that were asked included:

1. How does having a child with autism impact you? Your family?
2. How does school have an impact on the child with autism? You? Your family?
3. Tell me about your typical day during the school year.

The second interview, at the beginning of summer, was performed to record responses when parents were faced with the summer break. It was at the same meeting as the second PSI to represent the summer break and the second VABS. The second interview, based on the approach by Seidman (2006), was an interview about the concrete details of experience. Parents were asked to reconstruct details and tell stories about their present situation. They were asked for details, not opinions, at this interview. Questions that were asked included:

1. How does summer break have an impact on the child with autism? You? Your family?
2. Tell me about your typical day during the summer.
3. Tell me about day care, summer programs, or relief your child participates in.
4. How does this relief impact your child? You? Your family?
5. Tell me about any programs or education you may perform with your child over the summer yourself.
6. How does this programming or education impact your child? You? Your family?

The third interview, at the end of summer, was also based on the approach by Seidman (2006). The final interview was for parents to reflect on the meaning of their experiences. It was where they could share their opinions, their understandings, and their thoughts about the future. This was the longest of the three interviews, with only the VABS taking place at the same meeting. Questions that were asked at this interview were based on reconstructions from the past two

interviews. Parents were asked for their opinions, understandings, and thoughts about the future given certain interesting reconstructions they made in past interviews. Specifically, their opinions on and understandings of the root causes of some of the effects of summer break they previously reconstructed were asked about, with general questions such as “Why do you think that?” It was important to draw out some of these interesting reconstructions for parents to comment on because it was two months since the previous interview, and they may not have remembered what was said. As in all of the interviews, more information was drawn out by using questions such as, “Can you tell me more?”

The interviews were performed by the researcher and by two assistants who were hired by the researcher to perform the interviews with the parents of students in the researcher's own classroom. The interviews were digitally audio recorded. Notes were taken during the interviews when certain actions or facial expressions were important to the interpretation of the transcripts. The transcriptions were done by the interviewer, so that the interviewer could become more familiar with the interviews. This is important because the interviews were so far apart, and transcription helped keep them fresh in the mind of the interviewer between interviews. Also, while transcribing interviews, additional probing questions were composed for the following interview. This step was especially important for the interviews done by the assistants, so that the researcher could be involved in probing questions related to the research. The researcher also made notes during transcription, making future content coding easier.

2.5.1 Thematic Coding

The structure suggested by Seidman (2006), as described in his method of thematic coding, or what he calls classifying, data was used. Interviews were read for what was significant by looking at what was of interest and what was repeated throughout the interviews as they related to the research questions. These excerpts were coded into categories, and themes were looked for in the categories. Relationships between codes were also noted. The codes were based on what was in the interviews, not applied to the interviews from an external source. “The reason an interviewer spends so much time talking to participants is to find out what *their* experience is and the meaning *they* make of it, and then to make connections among the experiences of people who share the same structure” (Siedman, 2006). As Gibbs (2007) suggests, code definitions and

how the code relates to other codes were included in the memos, or researcher notes, so that the definition of each code did not unintentionally shift over the coding process. Content coding was performed with a combination of paper and pencil (or highlighter) and NVivo. NVivo is qualitative analysis software that assists with the analysis of text-based non-numerical data, making classification of large amounts of information easier. Tools such as “include synonym” in NVivo were used to create codes.

These codes were then interpreted by comparing them to other literature and looking at what was learned and what was surprising, comparing the qualitative and quantitative data, and including the basic demographic information. After content coding, participants were given the opportunity to read the themes and the quotes used in the discussion of the themes to member check the codes and verify that they were interpreted correctly by the researcher. Two participants offered to member check the codes.

2.5.2 Interpretation using Disability Theory

Interpretive research is defined as research framed within certain theories, such as feminist or disability study. Brantlinger et al. (2005) considers studies interpretive when they contain a critical element that questions the meanings of everyday life occurrences. Creswell and Plano Clark (2011) suggest using a theoretical foundation, such as an emancipatory theory, for looking at the research. Disability theory has been chosen as the interpretive theory to frame this research.

The influence of disability theory on this research is evident in three main ways, by looking at its impact on the subject, the methods, and the analysis of the research. First, the subject or topic of the research looks at how the educational environment impacts children with severe autism through breaks from school during the summer, taking a social model of disability perspective, because the format of the school year is socially created. Second, the methods used are mixed, and include interviews to find the story of those impacted by this environment, also taking a social model perspective. Participants are also treated as individuals, with individual goals being assessed, individual motivators being used, and even individual ways of determining the desire of non-verbal or low-verbal children to withdraw from the research. The third and most important way that disability theory is used in this research is through the analysis of the data,

particularly the interviews, the content coding of the interviews, and the application of disability theory to the codes. The social and medical models of disability, as well as combined models that stem from them, are applied to problems faced by students with severe autism and their families during the summer break from school. The way parents discuss their children's difficulties sheds light on which model of disability they use to look at their own child's autism.

3 Results

The results are first presented by looking at the statistical results of the quantitative measures including the Analysis of Variance on the Vineland Adaptive Behaviour Scale (VABS) and the individual education plan (IEP) goals, the t-tests on the Parent Stress Index (PSI), and the correlation of demographic information and test results. Then the thematic coding of the interviews is presented, including impacts of summer break, links between impacts, and needs and solutions given by parents interviewed. The changes in the VABS and the scores on the IEP goal assessments, as well as the parent responses about the impact of summer break on their children, are used to answer the research question of the effect of summer break on the academic, social, life, communication, and behaviour skills of children with severe autism and the recoupment of skills in the fall. The changes in the PSI scores and the parent responses about the impact of summer break on themselves are used to answer the research question of the impact of summer break on parents, including stress.

3.1 Demographic Information

All ten students were either in a self-contained intensive support class or at a self-contained school, with five in each. Eight of the participants had been diagnosed as severe by a psychologist, and two were in the moderate range, although all were considered to be severe by parents and teachers for the purpose of responding to the recruitment due to all of the students requiring very substantial support in school. Two families self-reported as making under \$25,000/year, four reported making between \$25,000 and \$90,000, and four reported making over \$90,000/year. There were two single parents and eight two-parent families. All but one parent was the natural parent; one was a foster parent. Each child with autism had zero to two siblings, with two having no siblings, five having one sibling, and three having two siblings. Three of the children with siblings had one or two of those siblings with autism themselves. One of the participants was female. Ages of the siblings were not recorded.

Hours of summer programming ranged from 0 to 100 hours over the summer. Relief ranged from 0 to 200 hours of formal relief, with one parent claiming 378 hours of relief from family. Relief was differentiated from programming. Care was considered relief if the primary purpose

was to give parents a break and not work on lessons or goals, and was considered programming if the primary purpose was to teach children with autism and not give the parents a break.

Formal relief is performed by a relief program or worker, while relief from family is considered informal relief. Parents also programmed with their own children from 0 to 200 hours over the summer. Parent programming was differentiated from other summer programming at autism programs. See Table 1 for student and parent pseudonyms and individual demographic information.

Table 1: Individual Demographic Information

| Child | Parent | Severity | Sibling #/ Autism sibling # ^a | Placement self- contained: | Parental Marital status | Economic status ^b | Summer Program hours ^c | Summer Relief hours ^d | Parent hours ^e |
|---------|------------|----------|--|----------------------------------|-------------------------------|---------------------------------|---|--|------------------------------|
| Ryan | Ange | severe | 1/0 | class | married | high | 0 | 12 | 18 |
| Joe | Christie | severe | 1/1 | school | single | low | 0 | 0 | 0 |
| Eve | Jhadxia | severe | 0/0 | class | married | med | 0 | 0 | 40 |
| Keith | Kate | severe | 1/0 | school | married | med | 0 | *378 | 0 |
| Jack | Nan | severe | 0/0 | school | married | low | 0 | 96 | 96 |
| Captain | Parker | severe | 2/2 | school | single | med | 0 | 200 | 0 |
| Sam | Rachel | severe | 1/0 | school | married | med | 100 | 40 | 200 |
| Y-Bean | Roadapples | severe | 2/1 | class | married | high | 0 | 32 | 0 |
| Lance | Kellie | moderate | 2/0 | class | married | high | 0 | 38.5 | 11 |
| Kay | KL | moderate | 1/0 | class | married | high | 60 | 0 | 0 |

^aNumber of siblings/ Number of siblings with autism

^bEconomic status high=>\$90,000, med=\$25,000-\$90,000, low=<\$25,000 family income per year

^cSummer program hours include programming done in autism programs

^dSummer relief hours include relief by summer relief programs, day care, or privately hired workers. *One parent reported relief by the grandmother, making it informal instead of formal relief.

^eparent hours include programming done by parents

3.2 Adaptive Behaviour Skills

One way repeated measures Analysis of Variances (ANOVA) on the four main domains of communication, daily living, socialization, and maladaptive behaviour in the VABS across the four time points was used to assess the impact of summer break on the adaptive skills of children with severe autism. Sparrows, Cicchetti, and Balla (2005) define adaptive behaviour skills as the performance of daily activities necessary to be socially and personally self-sufficient. The domains of communication, daily living, and socialization were standard scores ($M=100$, $SD=15$), while behaviour was a raw score as it did not translate to the standard score. See Table 2 for the descriptive statistics of these four domains. There were no significant changes between any of the time points, either over the summer or during the school year. Because standard scores are expected to stay the same relative to the sample, ANOVAs were also used on the raw scores of the nine subdomains of receptive, expressive and written communication; personal, domestic, and community daily living; and interpersonal, play and leisure, and coping socialization, and no significant changes were found.

Table 2: Descriptive Statistics of Vineland Adaptive Behaviour Scale

| | Communication Standard | | Daily Living Standard | | Social Standard | | Behaviour Raw | |
|---------------|---------------------------|----------|--------------------------|----------|--------------------|----------|------------------|----------|
| Time point | Mean | Std. Dev | Mean | Std. Dev | Mean | Std. Dev | Mean | Std. Dev |
| Spring | 64.70 | 15.80 | 66.70 | 16.10 | 66.30 | 23.80 | 21.60 | 8.02 |
| End of School | 65.10 | 16.64 | 63.00 | 13.69 | 65.70 | 24.66 | 20.80 | 12.05 |
| End of Summer | 64.80 | 19.19 | 65.80 | 18.74 | 64.60 | 24.28 | 25.00 | 13.48 |
| One Month in | 57.70 | 26.83 | 60.70 | 26.59 | 58.20 | 31.20 | 21.10 | 15.01 |

The standard scores of the domains of communication, daily living, and socialization were usually in the less than first percentile range, but went as high as the tenth percentile (in one domain at one timepoint), for the eight students who were formally diagnosed as severely

autistic. This means that 90% to over 99% of people in the same age range got higher scores in these domains than the students with severe autism in this study. Although no statistical analysis was done, it is interesting to note that the two moderate students had percentile rankings ranging from the eighth to eighty-sixth percentile rank. (This included rankings in three domains at four timepoints, so the eighty-sixth percentile rank was the highest of four assessments in the highest domain.)

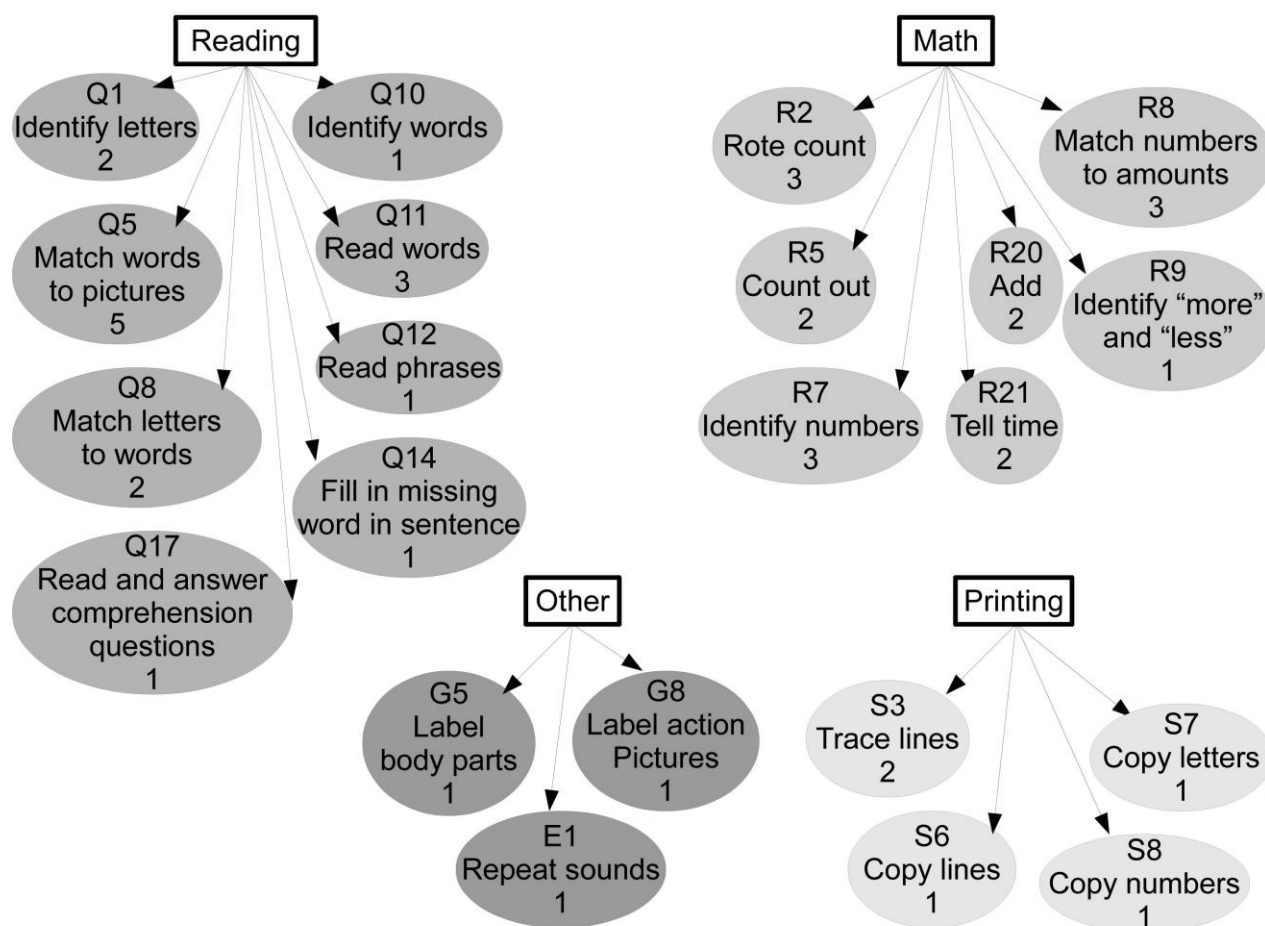
3.3 Academic Skills

Individual goals from the children's IEPs that were drawn from or based on the academic area of the ABLLS were used to assess academic skills over the same four time points as the VABS.

Two teachers used ABLLS goals from other areas as academic goals on the IEP. The goals that were taken from the ABLLS are shown in Figure 1. Two teachers used two ABLLS goals to create one IEP goal (for example, copy letters and numbers). In these cases, both ABLLS goals are included in the figure. Each goal has a letter/number code from the ABLLS first and is followed by the number of times the goal was chosen by a teacher for a student's IEP goal in the study. For example, the academic goal “telling time” is coded as R21 in the ABLLS because math is skill area R and telling time is the 21st math goal. Two teachers chose telling time as an ABLLS goal in the academic area of a student’s IEP.

A one way repeated measures ANOVA on the total percentage of the four ABLLS academic IEP goals at all four time points was used to measure the impact of summer break on the academic skills of children with severe autism in this study. The percentage of correct responses in chosen academic ABLLS goals for each student at each of the four time points, whether weighted ($F(3, 27)=12.733, p<0.05$) or unweighted ($F(3, 27)=12.563, p<0.05$), changed significantly over time. This calculation was done with percentages based on goals and with percentages based on parts of goals. For example, unweighted, each goal was totalled and then averaged, but weighted, a goal out of 26 (labelling letters) weighed 26, and a goal out of 50 (counting to 50) weighed 50. Denominators for each goal ranged from five for one student’s matching numbers to amounts to 130 for another students reading word list. See Table 3 for the descriptive statistics of IEP goals.

Figure 1: ABLLS Tasks in Academic IEP Goals



Each task has the letter/number code assigned to it in the ABLLS first and is followed by the number of times the goal was chosen by a teacher for a student's IEP in this study.

Table 3: Descriptive Statistics of Individual Education Plan Goal Assessments

| Time point | Unweighted % ^a | | Weighted % ^b | |
|------------------|---------------------------|----------|-------------------------|----------|
| | Mean | Std. Dev | Mean | Std. Dev |
| 1. Spring | 64.37 | 11.20 | 67.47 | 14.20 |
| 2. End of School | 79.96 | 11.80 | 83.02 | 12.46 |
| 3. End of Summer | 70.12 | 11.29 | 72.67 | 10.70 |
| 4. One Month in | 78.20 | 6.88 | 80.30 | 8.24 |

^aThe percentages of correct responses in each of the four skills were averaged to get the unweighted percentage. Each skill was worth 25% of the total score.

^bThe individual responses in each of the four skills were added up before converted to a percentage to get the weighted percentage. A skill that required twice as many responses held twice as much weight

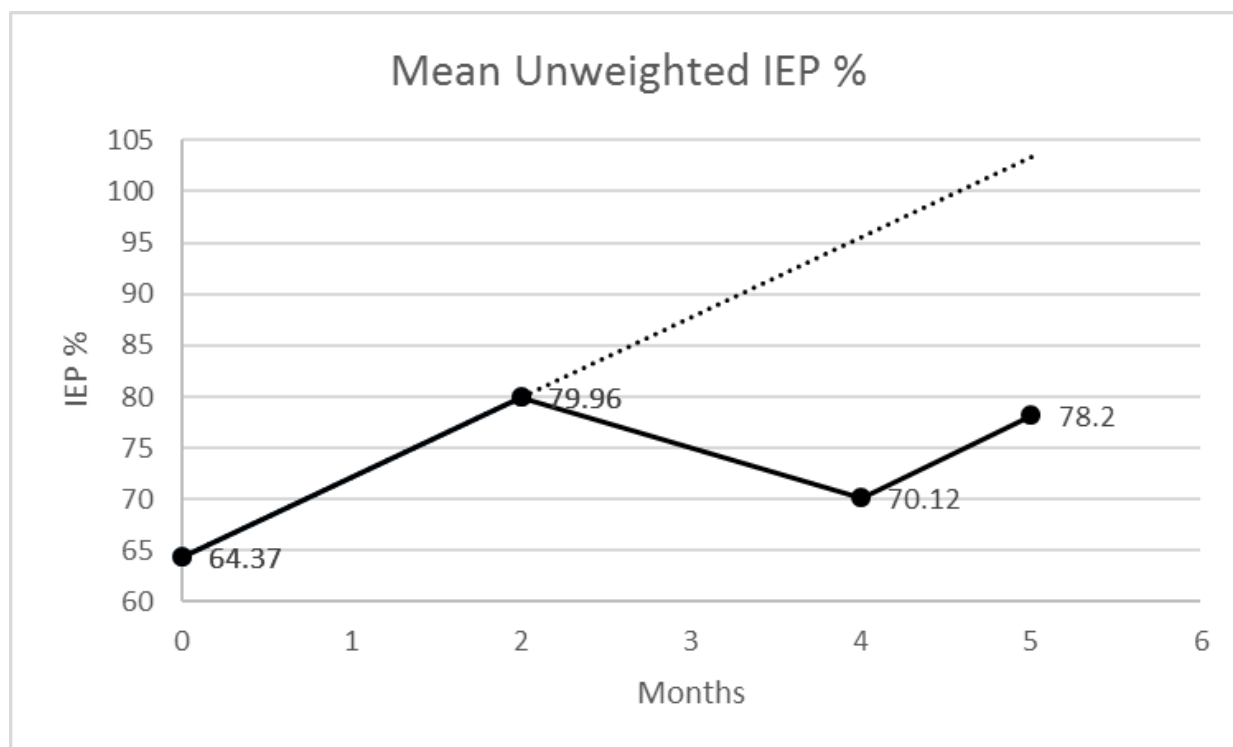
The number of acquired goals increased between spring and the end of the school year, decreased over the summer break, and went back up between the beginning of the school year and one month into the school year. The scores one month into the following school year were not significantly different from the scores at the end of the previous school year. All individual students lost some of their acquired skills over the summer break. All but one increased skills during the school year before the summer, and all but a different one increased skills again after the summer break. See Table 4 for the results of the Pairwise Comparison. See Figure 2 for a visual graph of the unweighted means including a linear prediction of learning if it is assumed that learning is linear and occurs at the same rate at all times and continues along the school trajectory over the summer, which may not be the case for all students.

The learning curve after the summer break when students were relearning skills is similar to the learning curve before the summer break. Students relearned at a rate of 8.08% of their goals per month after the break and 7.80% of their goals per month before the break. If it is assumed that

this learning slope is maintained until the student relearns up to where they left off at the end of the previous school year, then they will catch up at the 5.2 month mark, or 3.2 months after the end of the previous school year and be 25.1% of their goals behind where they would be if they had maintained learning over the summer break.

Table 4: Pairwise Comparison of Unweighted and Weighted IEP Goals at Four Time points

| Measure | time #1 | time #2 | Mean Difference % (#2-#1) | Std. Error | Sig. |
|------------|------------|--------------|------------------------------|------------|-------------|
| Unweighted | spring | school end | 15.6 | 3.9 | .018 |
| | spring | summer end | 5.7 | 3.2 | .630 |
| | spring | one month in | 13.8 | 3.0 | .008 |
| | school end | summer end | -9.8 | 2.9 | .047 |
| | school end | one month in | -1.8 | 1.8 | 1.000 |
| | summer end | one month in | 8.1 | 2.1 | .025 |
| Weighted | spring | school end | 15.5 | 3.5 | .010 |
| | spring | summer end | 5.2 | 2.8 | .551 |
| | spring | one month in | 12.8 | 3.3 | .023 |
| | school end | summer end | -10.3 | 2.8 | .028 |
| | school end | one month in | -2.7 | 2.2 | 1.000 |
| | summer end | one month in | 7.6 | 2.0 | .025 |

Figure 2: Descriptive Statistics of Unweighted IEP Goals

The four time points are represented in the graph by the number of months they are from the first time point. The first three time points were two months apart, and the fourth time point was one month into the next school year to assess for recoupment.

3.4 Parent Stress

Paired t-tests on the PSI measured the impact of summer break from school on parents of children with severe autism. The school year and summer break results of the PSI showed significant increases in the subdomains of child adaptability stress, which went up from a raw stress score of 30.40 to 33.40 in the summer ($t(9)=-2.09$, $p=0.03$) and child demandingness stress, which went up from a raw stress score of 23.60 to 26.90 in the summer ($t(9)=-1.88$, $p=0.05$). Increases in child adaptability stress indicates stress related to an increased inability to adjust to change, and increased child demandingness stress indicates stress related to increased demands on the parents. Parents experienced some significant increases in stress during the summer break.

The results of the PSI for the parents of the formally diagnosed severe students ranged from the 70th percentile to over the 99th percentile in summer and from the 25th percentile to over the 99th percentile during school. The higher the percentile rank, the higher the stress. The results of the PSI of the parents of the two students who were not formally diagnosed as severe ranged from below the 1st percentile to the 65th percentile in summer and from below the 1st percentile to the 70th percentile during the school, showing that the parents of the moderate students in this study had less stress, and that this stress was not impacted by summer break.

3.5 Correlation of Demographic Information with Tests

The demographic information, the total IEP and PSI scores at all four time points, the initial VABS standard scores and behaviour index, and the changes in IEP and PSI scores were intercorrelated using Pearson product moment correlations (r).

Child autism severity was correlated with the PSI total score during the school break ($r(8)=-0.74$, $p<0.05$), but due to only two levels of severity and only two students at the moderate level, this correlation may lack sufficient variability. A higher PSI scores demonstrates more stress, so parents of students with more severe autism showed more stress in the break, and parents of higher functioning students showed less stress in the break. Severity did not correlate with parent stress during the school year, nor with the change in stress from the school year to the summer break. Child autism severity was negatively correlated with the VABS standard scores in communication ($r(8)=-0.88$, $p<0.05$), living skills ($r(8)=-0.78$, $p<0.05$), and socialization ($r(8)=-0.86$, $p<0.05$), and positively correlated with the raw behaviour index ($r(8)=0.63$, $p<0.05$). The more severe the autism, the lower the adaptive skills in all areas, and the higher the level of functioning, the higher the adaptive skills in all areas, as would be expected. A high raw score in the behaviour index represents more maladaptive behaviours, so that more severe autism was associated with more frequent maladaptive behaviours.

Child placement also correlated with VABS standard scores in communication ($r(8)=-0.71$, $p<0.05$), living skills ($r(8)=-0.83$, $p<0.05$), and socialization ($r(8)=-0.79$, $p<0.05$). The more supportive the placement, the lower the VABS scores in communication, living, and socialization. Self-contained schools were ranked as more supportive than self-contained classes. Students from higher income families also have higher VABS scores in living skills

($r(8)=-0.76$, $p<0.05$) and socialization ($r(8)=-0.72$, $p<0.05$). Economic status also correlated with placement ($r(8)=-0.80$, $p<0.05$), with students from higher income families being in less supportive environments, and families with multiple siblings with autism were significantly more likely to be single parent families ($r(8)=-0.83$, $p<0.05$), but these two correlations lacked sufficient variability as seen in Appendix E. Participation in summer programs or relief did not significantly correlate with any total test scores, but programming and relief were extremely limited for all parents in the study. Parents reported hoping for more.

Unweighted IEP test results almost always negatively correlated with PSI total scores (significantly correlating with 7 of the 8 scores, all but end of summer unweighted IEP total scores with school PSI total scores). Two weighted IEP test results were negatively correlated with PSI total scores (The reported correlations involved the initial time point weighted IEP total score with school PSI total score and end of year weighted IEP total score with school PSI total score). See Table 5 for correlations of IEP and PSI scores. This correlation was with the test results of the IEP goals, not the change in test results over time. PSI total scores did not correlate with the changes in IEP test results over time. A higher score on the PSI demonstrates higher stress. The higher the academic skills, the lower the stress.

Table 5: Correlations of IEP and Parenting Stress Index Scores

| | Unweighted IEP | | | | Weighted IEP | | | |
|------------|----------------|------------|------------|--------------|--------------|------------|------------|--------------|
| | Spring | School end | Summer end | One month in | Spring | School end | Summer end | One month in |
| PSI School | -0.76* | -0.66* | -0.56 | -0.72* | -0.64* | -0.64* | -0.56 | -0.35 |
| PSI Break | -0.74* | -0.74* | -0.80* | -0.76* | -0.33 | -0.44 | -0.45 | -0.13 |

**df=8, $p<0.05$*

Only the initial unweighted IEP total scores during the school year correlated to the VABS

behaviour index; this correlation did not continue for the weighted IEP total scores or other time points. The changes in IEP total scores over time also did not correlate with the VABS.

Both PSI total scores during the school year ($r(8)=-0.78, p<0.05$) and during the break ($r(8)=-0.82, p<0.05$) correlated with the VABS behaviour index. The higher the stress, the higher the child's behaviour.

As expected, the results in the three standard score domains of the VABS – communication, living, and socialization - correlated with each other, but the behaviour index only correlated with the communication domain. Communication correlated with living ($r(8)=-0.95, p<0.05$), socialization ($r(8)=-0.95, p<0.05$), and behaviour ($r(8)=-0.68, p<0.05$). Living correlated with socialization ($r(8)=-0.97, p<0.05$). See Appendix E for graphs of the correlations.

Overall, as expected, severity was correlated with the PSI during the break, or parent stress during the break, and all of the tested domains of the VABS, or adaptive behaviour skills, including behaviour. The PSI, or parent stress, was also correlated with the VABS maladaptive behaviour and with unweighted IEP scores in academic areas.

3.6 Results Excluding Moderately Severe Students

Basic descriptive information was gathered, including formally diagnosed severity. The difference between the students who were formally diagnosed as severe and the two students who were severe enough to warrant a self-contained setting in school but were not formally diagnosed as severe was demonstrated during the correlation of severity with the VABS and the PSI.

When only the eight true severe students were taken into account, significant increases in the PSI in the subdomains of child adaptability stress, child demandingness stress, parent competence stress, and parent health stress scores were found during the summer. The parent stress areas of parent competence stress and parent health stress were not significant when all of the students were taken into account, but were significant for the severe students. Increased parent competence stress indicates stress related to a more limited range of child management skills, and increased parent health stress indicates stress related to a greater deterioration in health

(Abidin, 1995). Summer break has a significant impact on parent stress, especially for parents of children with autism who are diagnosed as severe. See Table 6 for the results of the Paired Sample Test comparing PSI during the school year and the summer break.

Table 6: Paired Sample Test of PSI on Severe Participants

| Measure | Pre-Post Mean Differences | Std. Error | t | Sig. |
|---------------------|---------------------------|------------|-------|------|
| Adaptability (raw) | -3.88* | 1.66 | -2.33 | 0.03 |
| Demandingness (raw) | -4.13* | 2.11 | -1.96 | 0.05 |
| Competence (raw) | -2.88* | 0.88 | -3.29 | 0.01 |
| Health (raw) | -1.88* | 0.74 | -2.53 | 0.02 |

* $df=7$

3.7 Parent Interviews

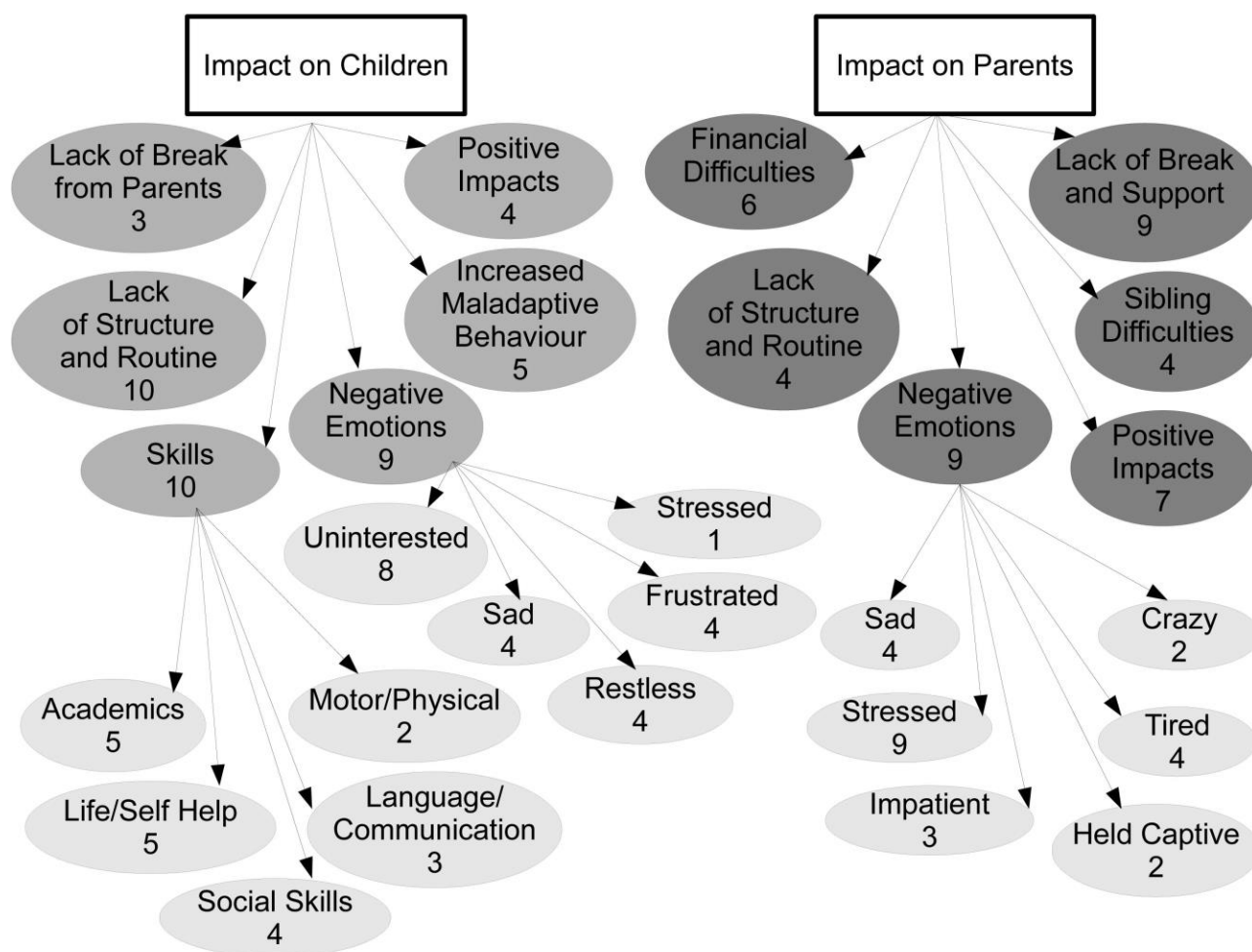
The parent interviews were analysed using thematic coding by first reading the interviews with the research questions of the impact of summer break on children with severe autism and their parents in mind. All discussion of the impact of summer break on children with severe autism and their parents was compiled by going through the interviews and highlighting the passages relevant to the impact of summer break. The discussions were categorized into codes and these codes were used to sort the material in the NVivo qualitative analysis software. The codes that were found for the impact of summer break on children with severe autism were emotions, lack of break from parents, lack of structure, increased maladaptive behaviours, skills, and positive impacts. Some of these codes were further divided into sub-codes. Child emotions were divided into sad, stressed, restless, frustrated, and uninterested. Skills were divided into academic, life/self-help skills, social skills, language/communication, and motor/physical. The codes that were found for the impact of summer break on parents of children with severe autism were emotions, lack of break or support, lack of structure, finances, sibling difficulties, and positive impacts. Parent emotions were divided into the sub-codes of sad, stressed, crazy, impatient, held

captive, and tired. Codes were determined by using terms from parent interviews, or synonyms that would encapsulate many terms with synonymous meanings given by different parents. The NVivo qualitative analysis software tool “include synonyms” was used extensively when making queries to decide which ideas to combine into codes and which to separate into different codes. This was especially useful for coding the emotions, because emotions can seem to range on more of a spectrum rather than in clusters. The “include synonyms” tool had a slider to include more or less similar synonyms, and set in the middle it assisted in sorting the emotions into the codes presented here. The codes that were found for the impact of summer break on children with severe autism and their parents, along with the number of parents who discussed each code, are shown in Figure 3.

Links between these codes were also found in the interviews. Parents made links between their child's emotions and both a lack of break and a lack of structure, while their child's behaviour was linked to both a lack of structure and emotions. A lack of break and lack of structure, as well as child behaviour and emotions, were also linked to parent emotions. The lack of break was also linked to sibling difficulties.

Finally, parents identified needs or gave solutions to the negative impacts. They suggested relief programs, structured programs, quality workers and programs, and funding. The interviews give a qualitative understanding of the impact of summer break on children with severe autism and their parents.

Two participants offered to member-check the codes by hearing the themes and quotes used in the discussion of the themes over the phone and commenting on the themes to check for bias and verify that participants were interpreted correctly during the coding of the interviews. Christina agreed with the themes and added that her son's maladaptive behaviours did go up over the summer even though this was not something she discussed during her interviews. She also reinforced that she needed respite. Kate also agreed with the themes and added that she also felt frustrated sometimes even though this was not a word that she used during her interviews.

Figure 3: Codes of Impact of Summer Break

Each code (first level codes) and subcode (second level codes) is followed by the number of parents that discussed that code in the interviews.

3.8 Thematic Coding of the Impact of Summer Break on Children with Autism

The codes that were found for the impact of summer break on children with severe autism were emotions, lack of break from parents, lack of structure, increased maladaptive behaviours, skills, and positive impacts.

3.8.1 Impact on the Child's Skills

The summer break had an impact on the academic, life/self-help, social, language/communication, and motor/ physical skills of the children in this study. All ten parents in this study talked about impact on skills from the summer break, with varied skills discussed by each parent. Jhadxia was “really worried that she's going to go right back to, um, forgetting, and that it's going to take two months, three months for her to relearn all the stuff that she's already learned.” Rachel said her child, “loses some of his skills, and some of the routines too.” She found that “a lot of times that [the school has] to start from the beginning when it comes to a lot of his skills” in September. Roadapples found that her child regresses over summer break, and even over Christmas and March breaks.

Kate found that summer had a negative effect on her child's education because “He hasn't learned very much. He's pretty much the same. He might have learned, you know.” Kellie agreed, “I don't think he really regressed, but I don't think that there was as much room for improvement as there would have been if he would have been in a more structured program.” KL also found that her child did not change much over the summer in general, but at this point her child was still in a summer program, and she talked about his maintenance in relation to what he does at the program, “I don't think Kay is necessarily losing any of his skills because lots of the time a lot of the things he'll bring home [from the summer program] will have his name on it with spelling and he says, 'See Mommy, I put my name on this craft'.” Parker also found no significant change in her son, but she also talked about the amount of one-on-one attention he got from relief workers.

The area of academics was the most difficult for parents to discuss because many did not

continue with academic programs into the summer at home. Five parents discussed academics. Roadapples admitted, “I don't know much when it comes down to numbers and letters and all that type of stuff because he won't play with me.” She continued to talk about how her child would colour with her during the school year, but “I've done that twice over the summer that I can remember and I tried to get him to join in and he would just lose it. So I'm not too sure really, aside of what type of academic, his academics would be with how he's regressed in that.” She went on to say that academic regression is not a big concern “at this age just because he's just like kindergarten, do you know what I mean? So, um, maybe I'd answer that question differently if he was like, seven, eight, you know, starting to go up in grades, but right now he's literally colouring and play making and button macaroni, so I'm not really concerned with his level of macaroni skills! [laugh].” Christie also admitted that, “I don't get him to do too much writing or stuff like, or, you know, looking at math or like, you know? Numbers or anything like that.”

Jhadxia worried about her child losing her reading and math skills over the summer. She found that over the summer, “her reading, like, she was at a level D, level E, I find that she just gets, it's uninteresting for her, she's getting bored. Um, I can just tell, like, at the beginning of the summer she, it was easier for her to do even math, like, it was easier for her to, like, tell time and all the worksheets. I find that she's getting, she's losing it.” Ange didn't see much change in education over the summer break. KL also found that her son was doing the same in academics during the summer, and found that to be lacking. Kellie was also upset that, “he didn't grow even more with his, you know, academics.”

Five parents discussed life or self-help skills. Christie found that her child regressed in “potty stuff” by peeing in his room. On the other hand, Kate's child learned how to pee standing up over the summer and Roadapples' child learned how to have a bowel movement on the toilet. Both Kate and Roadapples showed pride in their children's toileting accomplishments over the summer. Kate said it's something she was “very proud of because he's had, that's one of the things that I really want him to learn, because he is a boy.” Roadapples talked about cheering for her son's accomplishment. KL said life skills went down over the summer. Roadapples had difficulty with one life skill in particular, feeding. She called them “food funks”, and found that in school he would eat an entire banana or strawberry, but at home he'd only have a bite. But

then, when summer came, “about a month after school he stopped allow... I mean, he wouldn't eat.” He would also drink from a cup at school, but he won't do it at home, so that regressed over the summer too. Parker took an active interest in making sure her child maintained and developed life skills over the summer, having her child help with taking out the garbage, doing laundry, following road safety rules, and other self-help skills.

Four parents discussed social skills. Jhadxia found that her child, in the summer, “socially was worse. Like, she needs to be around people.” KL also found that social skills went down over the summer. Rachel found that “when he's not in a school setting or an education setting he tends to um, to not be as social.” Kate also found social skills lacking in the summer because there was no change, but “social hasn't been too bad [compared to life skills], because he is getting better with that I find as he gets older.”

Three parents discussed language or communication skills. Nan found that communication increased over the summer, stating that “the language, the speech, the words are coming out more and they are clear. There's more words coming out.” Parker also found that her child “acquired more language, and he was able to communicate a lot better than he used to, using words, sentences.” Rachel found that her son lost communication skills. “I think that because he doesn't have that regulated time where he's doing those activities... that he does lose some of that communication and some of those skills that he learns when he goes to school.” The difference between Parker and Rachel was that Parker found that her son had a lot of one-on-one time with his worker, while Rachel found that “when he goes to some programs they don't require him sometimes to, um, repeat or say his wants and needs so he kind of, like, he regresses a little bit when it comes to that.”

One other area that was discussed by some parents, but was not assessed by the VABS in this study, was motor or physical skills. Two parents touched on this area. Jhadxia enrolled her child in special needs soccer, and found that “she's getting better and better.” Parker also taught her child to ride a bike over the summer.

In summary, according to parents, academic skills either went down or did not change, but the lack of change was seen as negative by parents because their children could have been learning. Also, according to parent reports, life/self-help skills and communication skills went both up and

down (some parents reported increases and some decreases), while social skills went down or stayed the same and motor skills went up for the parents who discussed them.

3.8.2 Impact on the Child's Structure and Routine

All ten participants talked about the lack of structure and routine during the day their kids experience over the summer break. Ange discussed this the most. She repeated that her child lacked structure, saying “everybody seems more content [during school] and in the summer there is not as much structure. It's hard to make structure.” She continued, “He's just more difficult with changes in routine”. Christie found it hard to keep her two boys with autism busy in the summer. Jhadxia said that school was a very good routine for her daughter, and that she didn't have that routine in the summer. Kate said that her child was “very routine oriented” and that when his routine was broken “it's hard to get him back into the routine after he goes back to school”. Kellie wanted a summer program or day care with routine for her young child. Talking about her child's unstructured day care, she said, “I don't think that there was as much room for improvement as there would have been if he would have been in a more structured program.” KL said her child needed “more routine and more structure”. She said that in summer “he's out of his routines... summertime is not as structured as school was”. Nan said that her child needed to be kept busy in the summer. She was very clear about how she felt about programming in the summer: “This child had a ROUTINE. You do NOT take that away from those kids, because that's when he had too much time to destroy the house. He destroyed everything.” Parker felt that, in September, “it will be good to see him get back into routine”. Rachel also liked the routine of school for her child, calling it a “good routine for him”. She explained why routine was so hard to maintain at home over the summer. “I think school is, like, so, so important for him. I think it gives him structure that you can't give him at home because you come home and it's like there's other things to do, there's supper to make, there's wash to do, there's all these different things to do at home that you can't always concentrate on everything that the child needs all the time, and when they go to school, it's structured.” Finally, Roadapples claimed that at home during the summer “we don't have a schedule, I mean, we do things, but there's no, aside of eating and going to bed and waking up, that's the only routine that's really going on.” She also liked the routine of school for her child.

3.8.3 Impact on the Child's Emotions

Nine out of the 10 participant parents discussed their child's emotions during the summer break. The emotions were divided into five groups of synonymous or related emotions: sad, stressed, restless, frustrated, and uninterested.

The most prevalent emotion that parents claimed that their children faced during the summer break was disinterest. The code for uninterested included uninterested, inattentive, tired of things, unwilling, bored, unfocussed, harder to entertain, and less pliable. Eight of the ten participant families used one or more of these emotion words to talk about their child's feelings during the summer break. The concept that their children were not interested during their home hours during the summer break, but were interested during their home hours while they attended school was repeated by many participants. Ange claimed that her son “doesn't seem to have as much interest in doing things, like, you know, sitting down and doing puzzles together or doing whatever learning activity we might... like during the school year he comes home and he enjoys it.” She said later, “I just find it's harder for him to be as interested, like, sit and actually want to participate” in the summer as compared to the school year. Jhadxia agreed that, “I find that she just gets, it's uninteresting for her, she's getting bored. I can just tell, like, at the beginning of the summer she, it was easier for her to do even math, like, it was easier for her to, like, tell time and all the worksheets.” Later, she continued, “Even, like, swimming at the beginning of the [summer], she loves swimming, but now it's like she doesn't want to.” KL finds that “It's almost like I can't, and sometimes it's not, I can't keep him focused enough during the day sometimes, but school does.” Rachel believes that, “Sometimes he thinks during the summer that he doesn't want to do those things because, 'Well, I'm not in school'.” Roadapples found that, “He's harder to entertain, like, thing that, like the television, like he always wants to be doing something all the time, as when he was in school, he would either be pooped at the end of the day, you know, pooped. I'd come home and he's docile and pliable and I could work with him a lot.” Roadapples gave some examples of this pliability going away during the summer. One was that her son Y-bean had a character-themed workbook that he loved to hold and look at, so Roadapples tried to work with him from the book during the summer. “After that he didn't want nothing to do with the book anymore, a book that he had been holding for a week. You know, he loved that book. And then me doing that, now he hates that book. You know, because he's

associated with that. Whereas, like, if I had tried that say in school mode, he would have been a little bit more pliable because he was, like, colouring with me a little bit. You know, I would colour, I'd have to start colouring a book, and then he wants to join in, you know?" Roadapples called the school mode that she talks about "the mode" repeatedly throughout her interviews, referring to the pliability and willingness her son has at home during the school year as opposed to the summer. In the summer, she said, "it was sad to see some of his things go, like his willingness to do things. And it's not willing, like I don't mean willing like "yeah, let's do it", just being pliable at least. His pliability went away." When having difficulty working with her son during the summer, Christie wondered if, "maybe he will be more willing to work with somebody else". Kate and her husband found that their son got bored and tired of things he likes, like going outside, during the summer. Nan found that her son also got bored and tired of things he likes, like cutting paper with scissors, in the summer.

The code for sad included sad, depressed, not happy, and less content. Four of the ten participant families discussed their child's sadness. Most of the references were from Jhadxia, who, when talking about her daughter Eve, said, "She's very happy, she's a very happy girl, but you can just tell when she's, like, looking off, and then I always say, like, 'What's wrong, Eve? What's wrong?' And she's like [makes sad expression], and I'm like 'I want...', like I get her to say, sometimes it's like something that she wants to eat or she wants to go to the park or she wants to go outside, but sometimes she just looks sad, and she looks happier when she's in school." She called her daughter's mood in the summer depressed and sad. She claimed she sleeps longer. She called her "a better, happier person when she's in school". Nan agreed that her son Jack is "not a happy child" in the summer. Both Roadapples and Ange compared summer to the school year, Roadapples calling her son Y-bean happier and "more contented with coming home" during the school year than the summer, and Ange claiming that "everybody seems more content" during the school year than in summer.

The code restless included restless, house crazy, and hyperactive. Four of the ten participant families discussed their child's restlessness. Ange repeatedly discussed her son's restlessness in the summer. Kate said her child got house crazy and Roadapples claimed that summer affects her son's hyperactivity level. Christie claimed that "if you keep [her son] busy a lot, it helps."

The code frustrated included frustrated, intolerant, and agitated. Four of the ten participant families discussed their child's frustration. Roadapples said that, “With school, he's more tolerable, do you know what I mean? Like, he can tolerate a little bit more.” Ange found that her son is more agitated in the summer, and Kate found that her son “gets a little frustrated.” Rachel found that “whenever he's involved in a program, it helps. It helps him with the summer; it helps with his frustrations.”

The final code under child emotions was stressed, which also included coping less. Only one parent discussed their child's stress. Roadapples claimed that “not having the respite of going to school has had a tremendous effect on [his stress level] as well [as mine]” and found that “school is, I know for a fact, helps Y-bean cope better.”

3.8.4 Impact on the Child's Maladaptive Behaviour

Five of the ten parents interviewed talked about an increase in their child's maladaptive behaviour over the summer. Ange found that her child regressed in behaviour over the summer. She found “that his behaviours are more difficult to handle”. She explained, “He's more restless, he's more agitated. He's a little bit more aggressive. He's starting to hit and stuff like that, which he's never, ever done before.” At the beginning of the summer, Kate did not see any behaviour changes in her child, but by the last interview she found that behaviour was an area of change. Nan found that her child's behaviours increased over the summer break as well. She thought it was because “he's in the house seven days a week, when this child is used to going to school five days a week. She listed many behaviours: destroying things, bolting, and kicking objects and people. Roadapples found that her child regressed in “being able to pull him[self] forward out of his ruts when he isn't being engaged regularly, you know? He starts to regress, then he just kind of gets, primitive, you know?” Her husband agreed that “in the summer he's going backwards with his behaviour”.

3.8.5 Positive Impacts on the Child

Four of the ten parents in this study had stories of positive impacts of summer break on their child with autism. Christie talked about swimming and spending time outside, spending time with mom, and going to Dynamic Earth and Science North. She found that “it's nice for them to

have a break”. Kellie kept her child in soccer and went on what she called “little trips” over the summer. When asked about the Lego Centre trip, she responded “He loved it. He enjoyed it a lot.” Parker also discussed Science North, the beach, Cortina cruises, and bike rides. She found that her child “loves [summer]. He does, because he has an opportunity to do things”. Finally, Roadapples talked about a positive trip to the zoo. She said that she loved it and that her child was “generally pretty good”.

3.8.6 Impact on the Child's Break from Parents

Three parents discussed the lack of break their children got from them during the summer. Christie said that “kids need a break from you as well”, and “respite's not just for me, it's also for them,” referring to the break they got from school. Rachel said that her son “needs respite from us as well to do stuff with other kids and socialize with other kids other than just his brother and us”. Jhadxia found that she had difficulty getting her child to work with her over the summer. She found that her child saw her as mommy, and therefore not as a teacher. As she said, “home is home, school is school, like, she learns a lot better from other people”.

3.9 Thematic Coding of the Impact of Summer Break on Parents

The codes that were found for the impact of summer break on parents of children with severe autism were emotions, lack of break or support, lack of structure during the day, financial, sibling difficulties, and positive impacts.

3.9.1 Impact on the Parent's Emotions

Nine out of ten participant families discussed their own emotions during the summer break. The emotions were divided into six sub-codes: sad, stressed, crazy, impatient, held captive, and tired.

The most prevalent parent emotion was stress. The code stressed included stressed, having a hard time, finding it difficult, scared, anxious, nervous, and finding it sometimes bearable. Nine of the ten participant families discussed their own stress and the difficulty they were having over the summer. Ange used the terms difficult, hard, and stressful to refer to the summer break, saying it is hard to get things done and “it's hard to make the structure”. Christie repeatedly used

the word hard as well, saying “it's hard to always have the time to make for him”, “it's hard to keep them busy sometimes”, it's hard to “balance everything”, and “it's hard to pick a time to go shopping”, especially when her son “has a meltdown”. She claimed, “I'm pretty sure I'm not the only one that's finding it pretty hard when we don't have, what's the word, adequate summer programs for our children with autism.” Christie also used the terms “anxiety to the max” and “anxiety and a half” when referring to summer break. Jhadxia used the terms anxiety, hard, and stressful, sometimes repeatedly. She even found thinking ahead to the summer “hard, because I'm just thinking of the future. It's hard knowing that she's going to lose a lot of stuff that she's already learned in school”. She also found that “it's stressful because she's, it's, there's no time for me”. KL called the summer break “a little stressful at times”. Nan called summer break hard repeatedly, and even used the term scary when referring to her fear of her child running and getting hurt or dying. Parker used the terms stressful, anxiety, and nervous, but also said “I manage. I'm coping. I'm good.” Rachel used the terms difficult and stressful, as well as the term bearable when she has supports in place. She found “finding activities”, “organization... to get everything done”, and the “juggling new routines and trying to figure out different programs” stressful and difficult. She also found that it was stressful that “I can't be as effective as [the school staff] can be because I'm not in a controlled environment of a class”. Finally, Roadapples also used the terms hard, stressful, and difficult to talk about the summer break. She also asked, “How am I going to make it through the summer? Like, how am I going to do this?”

A separate code, but related to stress, was parents feeling crazy or losing their mind. Although this seems like a sub-theme of stress, the intensity of the language brought about its own sub-code. Two of the parents used this language. Ange said, “In the summertime, I go crazy”, and Roadapples said “I almost lost my mind”.

The code sad included feeling sad (for their children), feeling bad (for their children), and feeling better when their child is in school. Four of the ten participant families discussed their own sadness for their children. Jhadxia spoke about feeling bad for her child and feeling “really sad when she loses it, because she loses it really easily”. Kate felt bad when an incident happened in a store during the summer because the manager had to be called over to deal with an issue. Roadapples is also sad “to see some of his things go, like his willingness to do things”. Rachel spoke about her happiness when her child returns to school. She said, “it helps me feel better

during the day knowing that he enjoys going to school”.

The code tired also included spent, exhausted, mentally exhausted, and unproductive. Four of the ten participant families discussed their own exhaustion. Ange repeatedly said she was restless, and said “it doesn't seem like we have very much productive days during the summer”. Christie found that, “I'm the kind that I, you know, go to bed wide awake and wake up tired, but I don't sleep during the day because, you know, these kids”. Parker found that “I screw up a lot because I'm tired”. Finally, Roadapples found the day exhausting and mentally exhausting. She said that “everything I have as a parent gets brought to the table every single day. And if I have no respite and no routine in Y-bean's schedule, I'm spent.”

The code impatient also included intolerant. Three of the ten participant families discussed their own impatience. Ange found that in the summer she was more impatient with her child, and “not just with him, just in general, I guess”. Roadapples found that “not having the respite of going to school, that has had a tremendous effect on my tolerance level”. Rachel found that when her child was in a program, that her patience level was better afterwards. She needed the break and the time to de-stress.

Finally, two of the families discussed the idea of being held captive, or not being able to do anything as a result of the summer break. Roadapples found that she had some success on her holiday trips this summer, but found in other summers she was “held captive”. Nan talked about not being able to run errands, go to camp, or even go outside to have a BBQ because her child is a runner and she is unable to catch him if he runs. “We couldn't go anywhere”, she said. “You have to be with him all the time”.

3.9.2 Impact on the Parent's Break and Support

Nine of the ten parents interviewed talked about the lack of break or relief and the lack of support they get over the summer. Ange enjoys the break that school provides from September to June, and listed giving her a break as one of the most important features of summer programs or relief workers, in addition to structure. Christie said that the school year gave her a break. She said, “I don't know what I would do if I had the kids all the time and then, you know, I have to go to work.” Christie does not work during the summer because the childcare costs outweigh

her income. She has two children with autism, and even when she can get relief for one, the other prevents her from working, and “if Joe's gone and Kyle's not, it's not really relief for me”. She found it difficult to keep them busy, finding that taking them to the beach kept them busy, but “let's face it, there's days I gotta clean and do laundry. I can't always have them at the beach.” Jhadxia had no break either. She pointed out that her daughter is “actually a good girl, like she's never, you know, she's not bad, she's easy to take care of, but it's just not being able to go out and just go to the grocery store and things like that because she has a hard time with that.” She said that she and her husband go out at different times with their friends so that someone can stay with their daughter. When Kate was asked about getting relief in the summer, she answered with, “I wish.” Both she and her husband found the summer break too long. Even though her mother helps with relief so that they can go to work, she found the cost too high to hire a worker for relief for the times when she is not working. During the interview, the parents pointed out that “it's very difficult to talk when he's here.” The father continued, “He starts to talk over you, and then he starts getting progressively louder where you end up talking louder and louder and then he starts screaming.” KL was bothered by the lack of support from some family members. She found that stressful. She said, “it's easier for everybody when he's in school, whether my husband's working, I'm with the baby, it gives all of us a little bit more time from the demands with Kay, the constant attention, attention, attention sometimes on him.” Nan found that “you need a break, like, you need to go and relax.” Nan was a foster parent to her son, and her relief for the summer was cut. Parker got respite for her son, but she found that in the summer “We've had to pair down our night time respite because we use up the hours during the day for work.” She found that, “My typical day rarely, uh, even though I had a lot of respite hours, I rarely have time for me, so I actually had to schedule time for me and that's how I maintain my sanity.” She also talked about how it forced her to get a work-out in even if she didn't want to; she has to “grab the opportunity and go.” Rachel talked about all the things that she and her husband could do during the school year that they couldn't do during the summer. “If we have to do repairs on things and we don't want him to get hurt or painting things that have to be done, that's when we do it.” She found that she couldn't do it in the summer because when her child was outside he “needs 100% supervision, so you have to sit out there with them. You can't leave them.” So she found it nice to get “extra help, I think it's nice to have because it gives you that break.” Roadapples said “I need a break.” She found that her child “can't just sit and chill out with toys

and have a rain day” and that “if I have no respite and no routine in Y-bean's schedule, I'm spent.” She admitted to “giv[ing] into his demands for purely selfish reasons.” She said, “You know, I know that as a parent that that's not helping him. That's actually probably making my work harder down the road, but right at this moment it's what I needed... You know, if Doctor Phil was in my house or the Nanny from England there was in my house, 'Oh, no, that's not proper,' but, you know what? That's what got me through the day without losing my mind.”

3.9.3 Positive Impacts on the Parent

Seven of the ten parents also talked about positive experiences with their child with autism over the summer. Jhadxia found that “I'm doing stuff with her whereas last summer I really didn't do as much work with her. I feel like I'm getting more of a control of helping her a little bit more.” Kate claimed that her mother, her sister, and her daughter, who all help care for her child over the summer when she is at work, love taking care of her son. “My daughter just loves spending time with him, so, um, it's actually been OK. My mom likes spending time with him as well.” Kellie said she enjoys summer break. She enjoys not making lunches, and she enjoys “getting to spend the extra time with him and, um, I wish I could be home with him all the time.” KL talked about making summer fun for her and her child with autism. Parker found that she can have a better work schedule in summer because she doesn't have to worry about the school bus, and she talked about teaching her child how to bike. “He's learning to look left and right at corners even when I don't say so, and he's learning to put his bike away.” Rachel had a positive summer because she “had a lot of relief help and he was involved in some programs for, like, four weeks of the summer.” She found that the extra relief and routine made it “easier for him to, like, get through the days and for us to, like, be able to cope and everything with the extra time he's with us during the summer.” Even Roadapples, at the end of the summer, found the summer positive, “as opposed to other summer breaks where we were held captive.” She found that he travelled really well with breaks, but she was prepared for supplying these breaks.

3.9.4 Impact on the Parent's Finances

Six of the ten parents interviewed discussed financial difficulties related to summer. Ange said that she didn't get a lot of funding for their respite worker, so it didn't go very far. She also had

to turn down a spot in a day care over the summer when her husband got laid off. Kellie talked about the cost of things like occupational therapy and speech therapy when you don't have benefits. Christie couldn't work over the summer, because her job would not cover the cost of childcare for her two children with autism. She felt lucky that her boss was willing to hold her job until September, but she felt the financial hit. She even reorganized her finances so that the pay came out at different times over the summer to make it more manageable. When asked how else she manages, she answered, “well, I definitely don't go out and buy myself any clothes. [laugh]” She actually found that “money-wise, I was out on some money a month. So that's the biggest impact that [summer break] has on the family as a whole.”

Three of the parents who discussed finances spoke specifically about transportation to affordable or free programs being too expensive or inaccessible. Jhadxia's story was the most difficult. Jhadxia does not drive, so she was going to bring her child to the free autism program on the other side of town by bus. The bus ride would be approximately 45 minutes each way. She brought her husband the first time in case anything went wrong, because she was so anxious about it. She and her husband waited the three hours of the program on the other side of town and then picked their daughter up at the program. On the way back, the transfer bus downtown was late, and their daughter did not understand why they couldn't get on any bus to go home. Jhadxia explained:

We got to the bus station downtown and the bus was late. So, she did not like that very much and she started to cry and freak out and at that time she was even less verbal of really what she wanted. Now she can say no and now she has certain things like that. And she saw a bus and she wanted to get on that bus so she bolted for that bus. That was not the correct bus. It was full of busses and we had to hold her down. We had to hold her. And usually, especially because she's flailing, my husband had to hold her like a bear hug in a way. And as soon as we did that, stares everywhere, especially this one old man in particular, and we finally were getting on the bus this one man just looked at us and said “This isn't right,” like really getting mad at us like we were hurting her. And I was just, I couldn't believe it. No one's ever talked to me like that about her before, and we were trying. We finally get on the bus and he's going on the same bus and we were explaining it to him that she had

autism and that the bus situation... I was trying to do everything I could to get people to understand but no one... people didn't understand what autism was on the bus or they didn't care. And even elderly ladies, I had so many evil looks from people.”

Jhadxia took her daughter out of the summer program because she could not handle the stress of transporting her child. Jhadxia was clear that she did not blame her child, “I felt bad for her, I wasn't mad at her because it wasn't her fault. So, that's why we don't go there anymore. It's an importance of a bus, of a real bus, it's very important for that because then she would be able to go to school [at the summer program]. She would get that education.” Kate also lacked access to summer programs due to a lack of transportation because she and her husband both work full time, and neither her mother nor her daughter drive. They live too far from town to be able to drive their child themselves on their breaks. Kate said, “I would do anything if I could put him in a summer program, but if they had transportation it would be a lot easier on parents that work all week. You know what I mean? And that's a big problem. That's a huge problem for me because my husband and I want the best for him and want him to learn.” Roadapples also had an issue with transportation to programs in the summer because she lives so far from town that it would not be worthwhile for her to bring her child into town with her own vehicle because the time it would take and the cost of gas would only give her about two hours of relief to herself, and cost her a great deal each day in gas money. Roadapples required transportation, or more local summer program options.

3.9.5 Impact on the Parent's Structure and Routine

Four of the ten parents interviewed talked about the lack of structure in their own days over the summer break. Ange found that “the school year offers structure for all of us” and that “without the structure I find that... I'm restless because I'm tired.” Christie, who can't work over the summer, found that “I miss work, like when you get into a routine yourself.” Roadapples “can't wait to get back into routine” in the summer. Finally, Parker talked about her difficulty scheduling relief for her three children with autism in the summer. “The only stressor is that scheduling,” she said. She talked about problems she has had with scheduling, like when she schedules a worker too early or too late and she has to spend time at work trying to fill in the gap, or when workers call in sick.

3.9.6 Impact on the Siblings

Four of the ten parents interviewed talked about the impact that their autistic child's summer break had on their other children. Ange talked about her daughter, “We have a 14-year-old daughter too. It makes it difficult to try and do things as a family or to do things with her because, um, to try and find something that interests both of them is really difficult.” Ange found that summer programs or relief gave her more family time with her daughter. Nan also found that her autistic child's summer break had an impact on her other foster child. They couldn't take their autistic child to camp or even outside because he bolts very quickly and it is not safe, so that means they can't do anything with their other foster child either. “It's affecting [our other foster child] because she can't go swimming, right? She loves going to camp... But, can't do it.” Rachel found that relief made it easier because “if you have 2-3 hours during the day that they are with a worker, that you can maybe do something with your other child.” She did find that her other child was helpful. He “will sometimes sit down and do some colouring with him or trace shapes... so he's not sitting there doing it by himself because at school he has the other kids that are all doing activities as well.” Roadapples found that “not having the respite of going to school, um, that has had a tremendous effect on... the siblings of my autistic son's stress level.” She admitted to sometimes taking from her other children to give her autistic child his way to keep him calm, for example, making her other children stop watching a show on the TV because her child with autism is having a meltdown for a certain show. She knows it's not fair to the other children, but she says “if you want Mom to stay sane you need to stop what you are watching and put his show on.”

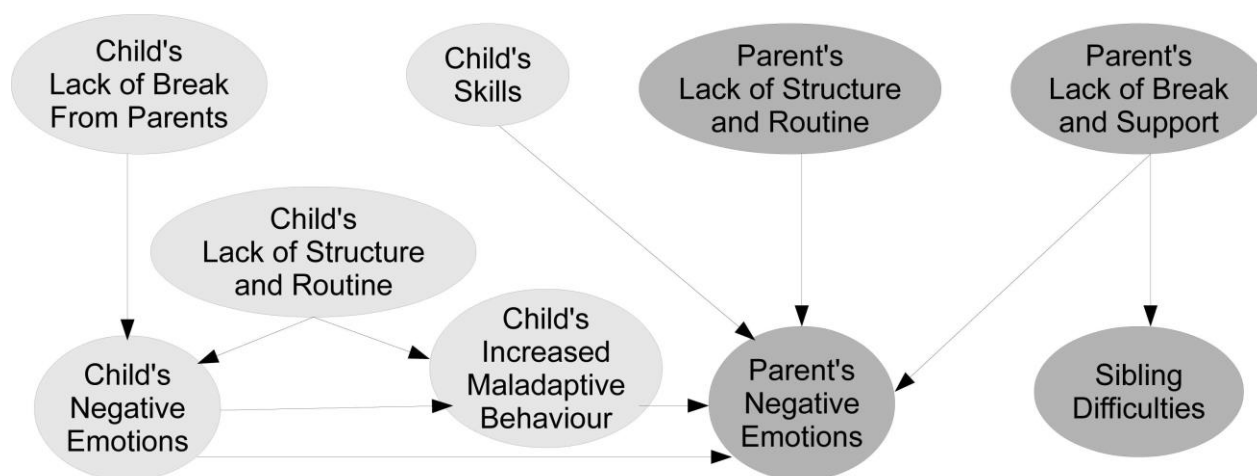
3.10 Links Between Impacts

Not only did parents discuss the impacts of summer break in interviews, they also discussed how those impacts related to each other. Each incidence of a parent linking one impact to another was coded, and the direction of the impact was included.

Child emotions were impacted by the child's lack of break and the child's lack of structure. The child's behaviour was impacted by the child's emotions and the child's lack of structure. Parent emotions were impacted by the child's change in skills over the summer, the child's behaviour,

the child's emotions, the parent's lack of structure, and the parent's lack of a break or support. Finally, the sibling was impacted by the parent's lack of support or break. These impacts are elaborated upon in this section and summarized in Figure 4.

Figure 4: Links Between Impacts of Summer Break on Children with Autism and their Parents



Child emotions were impacted by the child's lack of break. Roadapples found that, “not having the respite of going to school, um, that has had a tremendous effect on... his [stress] level as well.” Child emotions were also impacted by their lack of structure. Ange found that without structure in the summer, her child is restless and less content than during the structure of the school year. Nan found that without a routine her child is “not a happy child.”

Child behaviours were, in turn, impacted by the child's emotions. Jhadxia talked about how her child was mad when the bus was late (creating a lack of structure for the child), and this led to hitting her head, bolting, and flailing. Child behaviour was also impacted directly by a lack of structure. Ange found that “structure really, it's a huge change in his behaviours overall, like, he's more aggressive I'm noticing.” Nan stated simply, “This child has a ROUTINE. You do NOT take that away from those kids because that's when he had too much time to destroy the house. He destroyed everything.”

Parent emotions were impacted by child emotions. Ange found that when her son was restless, it made her restless. She found, “he gets really restless, and that makes us restless. Especially me,

because he comes to me mostly. So, it's stressful.” When Jhadxia continued to talk about her child's meltdown at the bus station and how her child “couldn't stop crying and we were comforting her”, she said that “all of us were crying by the end of that.” Parent emotions were also impacted by child behaviour. Nan was scared of her child hurting himself with one of his behaviours. She said, about his behaviour of destroying the mattress and getting inside it, “It's scary, he could die.” Parent emotions were also impacted by the change in the child's skills over the summer. Jhadxia said that, “it's hard for me, knowing that she's going to lose a lot of stuff that she's already learned from school.” Parent emotions were also impacted by their own lack of structure. Ange found that “the school year offers structure for all of us. So, it's just, everybody seems more content and in the summer there is not as much structure.” Roadapples said that, “If I have no respite and no routine in Y-bean's schedule, I'm spent.” Parents also found trying to create routine in the summer stressful. Roadapples found it stressful to have to “dance” for respite workers to get them to care for her child. She said, “that's what I love about school. It's respite for me.” Parker agreed that, “the only stressor is that scheduling.” She also had difficulty getting respite coverage for her children. Rachel also found that she was “more anxious when I know summer break is coming because it's that idea that I have to look into programs to see what's available, what's not. I have to interview workers usually from summer to summer because you lose workers from previous years.” She said, “the summertime is more stressful than during the school year because during the school year that routine is he gets on the bus, he goes to school.” Finally, parent emotions were impacted by the parent's lack of a break or lack of support. KL found that the lack of support from her husband's family was stressful. Roadapples found that without respite, she is “spent”, her stress level goes up, and her tolerance level goes down.

Siblings were also impacted by the parent's lack of break or support. Roadapples found that her other child's stress level increased without the respite of going to school too.

Looking at the links that parents made between various codes in the interviews shows two levels of codes, those that are impacted directly by the summer break from school, such as the child's lack of break, the child's reduction in skills, the child's lack of structure, the parent's lack of structure, the parent's financial difficulties, and the parents lack of support, and those that are secondary and impacted by the primary impacts, such as child emotions, child behaviour, parent

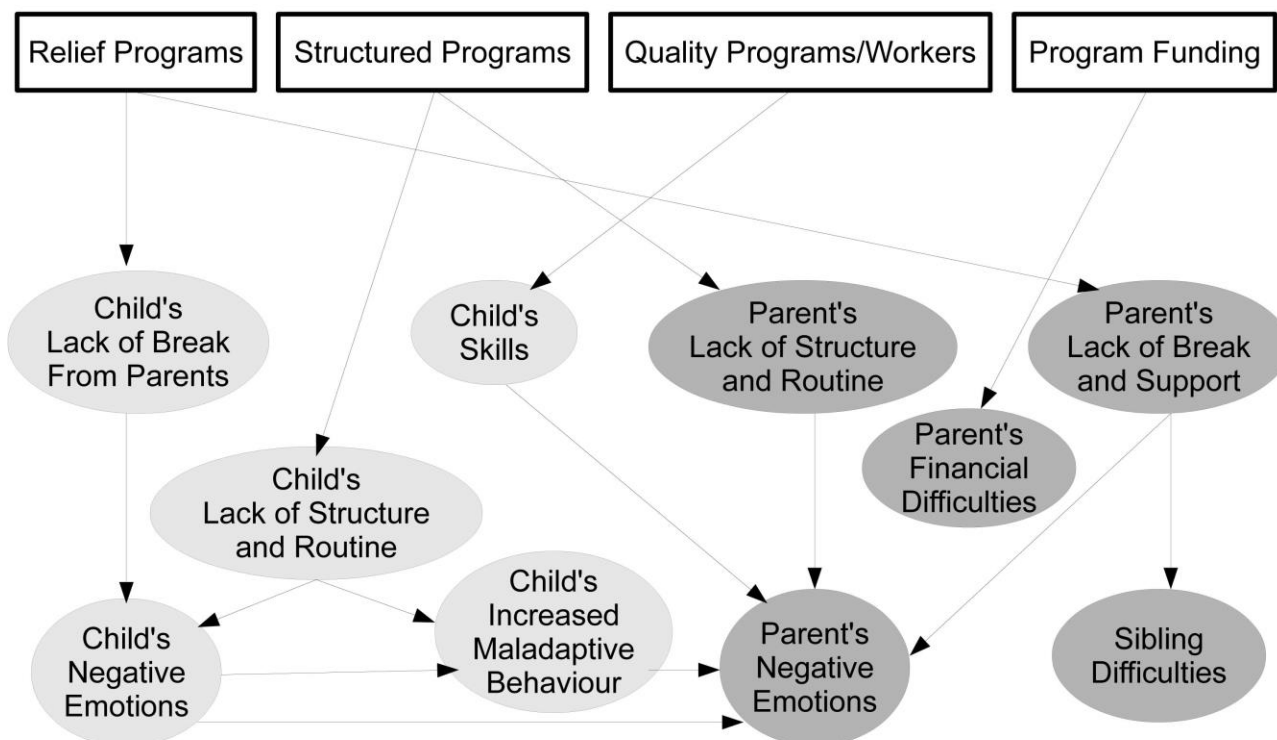
emotions, and siblings.

3.11 Needs and Solutions Given

Parents not only addressed the impact of summer break from school on themselves and their children, but they also gave some solutions to the problems. The solutions can be coded into four areas: programs that offer relief, programs that offer structure, quality programs and workers, and funding for these programs. Parent solutions solve the primary impacts of summer break from school. Programs that offer relief would be a solution to both parent and child lack of break. Programs that offer structure would be a solution to both parent and child lack of structure. Funding for these programs, including for transportation, would be a solution to the financial impacts of summer break. Finally, quality programs and workers would be a solution to any regression in skills that may occur, including behaviour. Parent solutions are not required for secondary impacts of summer break from school because if the primary effects are dealt with, the secondary effects will be minimized, or even non-existent. For example, if parent lack of support has an impact on siblings, then if that lack of support is solved, the impact on siblings should be minimized or non-existent. These needs are elaborated upon in this section and summarized in Figure 5.

Programs that offer relief would be a solution to both parent and child lack of break. Jhadxia, Kate, and Nan all thought that it would be good to have relief, but they did not have it at the time. Jhadxia said “it would be nice to have more support”. Kate said that “it's not always easy to get sitters.” Nan wanted her foster son “in a program where he could have been out of the house.” Ange, KL, Rachel, and Roadapples had some relief at the time, and they all discussed how the break from this relief made their lives easier. Ange said that it gave them “more family time” with their daughter, who did not have any similar interests to their son with autism. KL said she was “thankful for it because it gives me that extra time in the morning with the baby.” Rachel said that it's good “for us to, like, be able to cope and everything with the extra time that he's with us during the summer.” Roadapples said that the first things she did when she got home from camp “was call my respite worker.” She likes to get some respite from her son's “energy level”.

Figure 5: Solutions to Needs and the Impacts of Summer Break They Influence



Programs that offer structure would be a solution to both parent and child lack of structure. Seven of the ten parents interviewed talked about the need for structure and the solution of a structured program for their children with autism. Ange wanted her child's day care to have more structure. She found that during the summer “structure, really it's a huge change in his behaviours overall, like, he's more aggressive, I'm noticing. When he's at school, like, he's not like that. Like, he's so easy and I have no complaints. In the summertime I go crazy. So I just think that the day care would offer that same type of structure that a school program does.” Kellie also found that “At day care there's not a lot of structure. Um, I would prefer that he was in a program that has more structure.” She wanted structure and “a solid routine.” She added, “I don't think there was as much room for improvement as there would have been if he would have been in a more structured program”. Rachel also said, “I know it's a program for respite and the point is to give the parent relief, I'd still like it a bit more structured than what it is.” Jhadxia stated more than once that her child needs structure. She found “it's just better at school.” She “can just tell when she knows she has to go to school and she knows she has to, like, that whole structure of it just really makes a difference.” Nan feels that “the best thing that can ever happen

to him is to go back to a regular routine”. Roadapples finds her son needs “to be active and engaged all the time”. One parent, Parker, found that “we have been able to get into a routine” with her workers, and as a result “there's no real impact [of summer break] because it's a routine set in stone so everything just flows.”

Structure for parents looks a little different than structure for children. Children need the activities throughout the day to be routine and structured. Parents need the structure of day-to-day relief, not wondering if relief will be cancelled at the last minute or if they will have to beg for someone to provide support. Christie pointed out the problem of being given money, but then having to find the relief yourself. “When you are just given money and then, you know, you get a list... I got a couple lists and then you know, I tried calling some people. 'Oh, I'm having a baby; I'm not doing it anymore'. Then why not say get me off the list?” Other parents had problems with having to arrange workers on their own. Parker said that “it's stressful because I spend all my time fuckin' scheduling” and “I spend my time and energy fuckin' rescheduling during my work time, on my breaks.” Rachel said, “we're running back and forth trying to find activities and trying to hire workers so that we have a little bit of a break because we need to, like, to power up to be able to go to the next day to be able to do it all over again”. She said, “it's more stressful in that the organization has to be there to get everything done, and I think during the school year not so much.” Roadapples would also prefer a program to just money provided for relief workers or even using family because she found that with her respite worker or family she had to “do a little dance”, “play mind games with them”, and “kiss their ass”. She liked the idea of a program like day care because, “They're going to take my kid, I know they are going to take my kid, and I don't need to do that, and of course I'll be nice and maybe over time I'll talk to the people in a more personable way, but at least it's not something that I have to play out this big dance like a bird trying to mate another bird just so they'll watch my kids.”

According to parents, funding for these program, including for transportation, would be a solution to the financial impacts of summer break. Although there is some funding for relief, and there are some funded summer programs, four parents discussed the need for funding for transportation to these programs for parents who live a distance from the program, don't have a car, or don't drive. Jhadxia's heart wrenching story about taking her daughter to an autism program on the bus displays why public transportation does not always work for these families.

Jhadxia said that “that's why we don't go there anymore. It's an importance of a bus, of a real bus, is very important for that because then she would be able to go to school. She would get that education.” Kate also found that “transportation is a big problem” with summer programs. She felt that “transportation, it would be nice”. Rachel pointed out that “we don't have to bring him to school, but in summer programs we have to get him there, get him back.” “Also,” she added, “we have to have the funding. We don't have that much funding during the year, so we really, when we divide it up, we don't really have that much funding.” Roadapples said, about a summer program she qualified for, that, “for the amount of time that I'm travelling and the amount of money and gas it costs and him only being there a week it just didn't... because of my location, it just didn't seem worth the bother so I said no to that”. Roadapples lives a good distance from town. She did suggest “some sort of school bussing system” that would pick up kids in her area.

Quality programs and workers could be a solution to any regression in skills that may occur, including behaviour. Parents wanted the following qualities at summer programs: a high level of staffing, up to some one-on-one time; a variety of programming areas, including life skills, social skills, academics, communication, and motor skills; workers that parents trust and feel their children are safe with; workers who are skilled and knowledgeable in autism; and workers who can deal with their children's behaviours.

Parents who wanted a high level of staffing included Ange, who complained that the day care she wanted “won't have enough staff to really keep an eye on him”, and Christie and Rachel, who thought that their children needed more one-on-one in summer programs. Kate and KL found that one-on-one support in school helped their children. Christie and Kate wanted to see life skills programs. Christie, Jhadxia, Kate, Kellie, and Rachel all wanted to see academic programs, or what some of them called “work”. Christie, Jhadxia, Kate, KL, and Parker all wanted to see social skill development. Kate wanted to see speech and motor programs, and Rachel wanted to see computer training.

Parents want to trust the workers that their children are with, and to feel that their children are safe. Ange said, “I have, like, a real big trust issue. I don't trust nobody.” Jhadxia agreed that, “I don't really trust her with a whole lot of people.” Rachel was worried “with the program that

there's safety features in place, that it's in a safe area.” She did not feel “at ease all the time while he was at respite”. Christie also wanted her child kept safe. Parents also want workers who are skilled and knowledgeable in autism. Rachel wanted “experienced workers” who were “knowledgeable about autism, because some of them are not and it's a little bit worrisome when, um, they don't know about, like, his toileting issues or about his speech issues, or his difficulty with routine”. Rachel did find a worker herself who was not through a program, and she “thought that the standards of her experience was so much higher than the workers for the city program.” Parker called the city programs “brutal, because the people were, like, sun tanning all day”. She also found her own workers and trained them herself. Some parents even wanted “specialized day care”, even though “it's nice to have kids with autism integrated in day cares with other children, but I also think that there's some cases where the children need more, you know, one-on-one.” KL would also prefer “an autism based [program] for sure. Like, I wouldn't want to send him to just a, I would want to have people there who are, you know, familiar with strategies for autism.” Ange admitted that the regular programs “won't have enough staff to really keep an eye on him”. Related to wanting knowledgeable and experience workers, is wanting workers who can deal with their child's behaviours. Christie wanted workers who “could actually deal with, you know, behaviours”. She said, “I know there's a safety issue, but still, like, you know, if you can't, like, have somebody working with autistic children for three hours that can't even kind of deal with that, I don't know.” She told a story about how her child was kicked out of an autism summer program for escape running. Nan said that she was told that her foster child was “too high maintenance. No day care would take him” because of his behaviours. Parker said that it's important that workers “follow through with the command and... stick to the program”.

Nan found that, “those kids [with severe autism] need [summer programs] more than anybody else. And they have programs for normal kids anywhere in town.” They are the ones that need the structure, the relief, the quality care, and the funding. Parents feel that these four items in a summer program for their children would reduce the impact of summer break on their children and themselves. Parents feel that people should be more educated on children with autism (Kate) and be a little more tolerant (Christie). Jhadxia felt that the way they were treated in public when her child was having a behaviour was “almost like bullying”.

3.12 Summary

The children with severe autism in this study lost significant academic skills over the summer break, and significantly recouped those skills over the first month of school in the fall, as shown by the ANOVA of the academic ABLLS goals on the children's IEPs. The qualitative interviews reinforced the losses found in the quantitative part of the study. Life/self-help skills and communication skills went both up and down (some parents reported increases and some reported decreases), social skills went down or stayed the same, motor skills went up, and behaviours increased according to parent interviews, but the VABS did not show school year progress or summer regression. Significant decreases in child adaptability, child demandingness, parent competence, and parent health were found during the summer by t-tests on the PSI. Finally, a qualitative understanding of the impact of summer break on children with severe autism and their parents was found by the content coding of the interviews. Impacts of summer break on children with severe autism were emotions, lack of break from parents, lack of structure during the day, increased behaviours, impact on skills, and positive impacts. Impacts of summer break on parents of children with severe autism were emotions, lack of break and support, lack of structure during the day, financial, sibling difficulties, and positive impacts. As hypothesized, parents did enumerate child behaviour as a cause of parent emotion, among other given causes. Parents also gave four solutions to needs of children with autism and their parents over the summer, including relief programs, structured programs, quality programs and workers, and program funding.

4 Discussion

The results of this research are discussed in light of the literature review and the relationship between the qualitative and quantitative data. Solutions and recommendations are provided. The findings are then looked at through a disability theory lens. Limitations and future research are discussed.

The purpose of this research was to investigate the effect of summer break on the academic, social, life, communication, and behaviour skills of elementary children with severe autism and to assess the recoupment of skills in the fall. It was hypothesized that students with severe autism would regress in academic, social, life, communication, and behaviour skills, and would require over one month to recoup these skills. The secondary purpose of this research was to assess the impact of summer break on the stress of parents of children with severe autism. It was hypothesized that parents would feel more stress during the summer break than they do during the school year and that they would give maladaptive behaviour as a source of this stress. In addition to the research hypothesis, this study aimed to show a qualitative understanding of the impact of summer break on children with severe autism and their parents. It is this qualitative understanding of the impact of summer break and how the various parent and child impacts are interrelated that forms the basis of this discussion.

4.1 Impacts of Summer Break

The most relevant finding of this research is the relationship between parent negative emotions, specifically stress, and other impacts of summer break. Parents cite a decrease in skills, increased maladaptive behaviours, negative child emotions, and their own lack of break and support as impacts of summer break that in turn influence their own emotions and stress. This interrelatedness goes even further when parents cite impacts of summer break that influence other impacts that in turn influence parent stress. The child's lack of break was found to impact the child's emotions (which influenced parent emotions) and the child's lack of structure was found to impact their behaviour (which also influenced parent emotions). There are two levels of impacts, the primary impacts that are impacted directly by the summer break from school (lack of break, lack of structure, child's skill, and financial difficulties), and those that are secondary

and impacted through the primary impacts (emotions and behaviour). Because parents link other impacts of summer break to stress, a variety of solutions and recommendations can be suggested that address the other impacts, and in turn, address parent stress. Parents made these recommendations in the interviews. These recommendations can each be linked to primary impacts.

The discussion will begin by looking at the impact of summer break on parent stress and then discuss the other impacts that are linked to parent stress. It will then move on to the solutions and recommendations provided by parents.

4.1.1 Parent's Stress and Other Emotions

In the review of the literature on the impact of having a child with autism on parents, the parents experienced more stress and other negative effects than parents of children without disabilities and with other disabilities. This previous research did not compare these parents at different times (ie. during the school year and during the summer break), but compared them to other parents. Still, it gives a good idea of the emotions that are related to caring for a child with autism. In this research, the PSI t-tests showed significant increases in child adaptability stress and child demandingness stress during the summer, both areas in the child domain that contribute to total stress. The codes that were found for the impact of summer break on parents of children with severe autism in this research included “parent emotions”. Nine out of ten participant families discussed their own emotions during the summer break. The emotions were divided into six sub-codes: sad, stressed, crazy, impatient, held captive, and tired. The most prevalent parent emotion was stress. The code stressed included stressed, having a hard time, finding it difficult, scared, anxious, nervous, and finding it sometimes bearable. Stressed was the most commonly cited sub-code under parent emotions, with nine of the ten participant families discussed their own stress and the difficulty they were having over the summer. Although given its own sub-code, the sub-code feeling crazy is also related to stress, and shows the depth of the emotion that parents often feel. One parent says that she almost lost her mind over the summer. Both qualitative and quantitative sources point to an impact on parent stress over the summer break. Although there is a large body of evidence that parents of children with autism experience stress, this research makes the unique contribution of showing that summer break adds to this

parent stress.

Previous research has found that child variables that influence levels of parent stress include adaptive skills (eg. Hall & Graff, 2011). The codes that were found for the impact of summer break on children with severe autism included an impact on skills (including adaptive skills). Child skills were broken down into academic, life/self-help, social, and language/communication. An impact on these skills was found to have an impact on parent emotions, specifically parent stress, consistent with the literature.

IEP test results correlated with PSI total scores. The higher the IEP test results were, the lower the parent stress that was experienced overall. This correlation was with the results of the IEP testing, not the change in the results over time. This is significant because the IEP test results are not based on a standardized test, but on individual goals. If the goals are made too difficult by the teacher, the student will do poorly. If the goals are made easier, the student will perform better. It is said by teachers and consultants in the profession of special education that if a child on an IEP does poorly, it is the fault of the teacher for writing an inappropriately difficult IEP, not the fault of the student. The impact of this on the family is that students who did poorly, because of IEP goals that were too difficult to accomplish in the term, had parents with more stress. Following this, parent stress can be reduced by educators making appropriate IEP goals for their children.

Research has also found that child variables that influence levels of parent stress also included problem behaviour (Phetrasuwan & Miles, 2009; Rao & Beidel, 2009). The PSI total score was correlated with the VABS behaviour index. The higher the child's behaviour, the higher the parent stress. Also, increased maladaptive behaviours was one of the codes used for child impacts of summer break in the parent interviews. Increased behaviour was found to have an impact on parent emotions, specifically parent stress. Both qualitative and quantitative data support the relationship between behaviour and parent stress, and the findings of this research are consistent with the literature review.

Autism symptom severity has also been found to be a child variable that influences the level of parent stress (eg. Ingersoll & Hambrick, 2011). In this research, autism severity was correlated with the PSI during the summer, but not the PSI during the school year or even the change in

stress from school to summer. Parents of children diagnosed with severe autism have more stress in the summer than parents of children with less severe autism. Although this research is consistent with the literature review in that it agrees that autism symptom severity contributes to parent stress, it adds that this is specifically the case during the summer break.

Child emotions, lack of structure, and lack of support also have an impact on the parent's emotions, with stress specifically given as an emotion affected in all cases. Interestingly, stress was never attributed to financial issues related to the child with autism in the interviews. This may have been because finances may not be a significant source of stress, finances may be too personal to discuss, or the impact of finances may have been assumed by parents.

4.1.2 Academic and Adaptive Skills

The review of the literature on the impact of summer break on the achievement of students with special needs showed losses in both math and reading (Allinder & Eicher, 1994; Cornelius & Semmel, 1982; Cortex & Hotard, 1984; DeVito & Long, 1977; Shaw, 1982) and no changes in math and reading (Allinder & Fuchs, 1991; Beatty, 1985; Cortex & Hotard, 1984; Franklin, 1987) over the summer. In this study, significant losses were found in goals taken from the ABLLS and used in the academic area of each child's IEP by using one-way repeated measures ANOVAs with the percentage of correct responses. Significant results were found when calculating scores based on number of goals or based on parts of goals (for example, goals with more parts, such as counting to a higher number, were given more weight). Parents also reported that their child's academic skill either went down or stayed the same over the summer in interviews. There was concern that staying the same was a problem because it was not learning. One parent of a younger child was not concerned about academic regression, calling it “macaroni skills” at his age, but other parents were worried. One of the main concerns with academic skills going down is the same as the concern the parents in the interviews had with skills staying the same: students could be learning, but they are not. Students with severe autism often learn at very slow rates, and when this learning is disrupted, it slows it down even more. Both qualitative and quantitative sources in this research point to a negative impact on academic skills over the summer break. The findings of this research are consistent with the findings in the literature on the impact on students with special needs, but only the Handleman and Harris study (1984)

looked exclusively at children with autism, and it only looked at word recognition, so these findings bring new information about overall academic skills to the body of research.

In the review of the literature, recoupment times were reported to take anywhere from two weeks to over eight weeks for students with special needs (Allen, 1984; Allinder & Eicher, 1994; Menouskey, 1983; Waugh, Fredrick, & Alberto, 2009; Wilkins, 1983). In this study, students recouped skills within four weeks of returning to school in the fall. Because only one recoupment test date was used at the one-month point, it is not clear at what point before the four week mark that recoupment was significantly acquired, but four weeks was chosen as the acceptable length of recoupment time to test by the researcher. This finding is consistent with the review of the literature being within the two to over eight-week range. The concern with a long recoupment time is the same as the concern for the summer break: students are not learning. They are only recouping what they already knew, and the time is not spent on new learning. For students with severe autism, who often learn very slowly, this makes learning happen even slower. If learning before the summer break is projected to increase at the same rate, and this is compared to the level of students after recoupment, students acquired 25% less of their goals after the impact of summer break.

Losses were also found in the review of the literature in other areas of special education, such as adaptive skills (Allen, 1984; Menousek, 1983; Wilkins, 1983). Adaptive skills include life or self-help skills, communication skills, and social skills. Adaptive skills were tested using the parent rating scale of the VABS. The VABS did not show progress during the school year or regression over the summer. This could have been due to a lack of progress, or a lack of sensitivity in the test. If the VABS was not sensitive enough to show progress during the school year for the students, the lack of change over the summer may be (and most probably is) due to this lack of sensitivity. The VABS may not be sensitive enough because the tasks that it asks about may not include the goals of the individual students, and if it does, the response options are only usually, sometimes/partially, or never. So if the goal was to name ten objects, and the student went from knowing seven to four, the parent would consider both levels as partially completed, but the change would have been significant according to the child's goal. In the literature, direct observation (Allen, 1984), IEP goals (Menousek, 1983), and various tests related to each child's goals (Wilkins) were used to assess adaptive skills. Although the quantitative

research did not give significant results, the parents discussed adaptive skills in their interviews. According to parent reports in the interviews, life/self-help skills and communication skills went both up and down (some parents reported increases and some reported decreases), while social skills went down or stayed the same.

Parents were very emotionally invested in many of the adaptive skills, for example, toileting skills. Toileting skills were the most commonly discussed self-help skill, with mixed results. The parent whose child regressed was unhappy, and the parents who had success were celebrating. This emotional investment in life/self-help skills and communication skills could be responsible for the reported increase in these skill areas. Parents worked on these areas with their children, while many parents reported not working on academics during the summer. The losses in social skills would be expected, as parents cannot provide the same social experiences as a classroom for the same length of time during the summer, even if they felt emotionally invested in this adaptive skill. Parents reported more positive changes in life and communication skills than the literature review, but similar results in social skills. It would have been interesting to collect and compare quantitative data on regression in communication and life skills based on the student's IEP goals in these areas with the qualitative results of the interviews with parents to see if they triangulate, especially in light of the fact that the literature review did not find progress in these areas over the summer, but some parents in this study did find some.

4.1.3 Maladaptive Behaviour

Increases in maladaptive behaviour were found in the review of the literature (Allen, 1984). Maladaptive behaviour was also tested using the parent rating scale VABS, which did not show either progress or regression, in this research. As discussed above in adaptive skills, the VABS does not look at the specific behaviour goals of the individual students, but at a list of general behaviours. The possible ratings of these behaviours were also quite general, with the response options being often, sometimes, or never. Even if a student had one of the general behaviour as a goal, an increase or decrease in this behaviour may not register on the VABS if the increase or decrease was still considered "sometimes". For example, similar to the adaptive tasks, if the goal was to stop biting fingernails, and the student learned to only bite their fingernails once a week, but then went up to three times a week, the rating parent might still consider both of these as

“sometimes”, although this is a considerable increase based on the child’s goal. In parent interviews, parents found maladaptive behaviour to have increased. All of the parents of children with increased behaviours were concerned about them. The findings from the parent interviews were consistent with the findings in the review of the literature. As with the other adaptive behaviour skills, it would be interesting to collect and compare the quantitative data on behaviour based on the student’s behaviour IEP goals with the results of the parent interviews. The child’s emotions and the lack of structure contributed to the child’s increased maladaptive behaviour according to parents in interviews. The child’s emotions were also impacted by the child’s lack of structure, making the lack of structure the code that is the primary contributor to child maladaptive behaviour.

4.1.4 Child's Negative Emotions

Although emotions were sub-coded into five emotions: uninterested, sad, restless, frustrated, and stressed, the sub-code uninterested had twice as many parents discuss it than any other emotion. Many parents discussed how students were more interested at home when they had been at school all day, which is counter-intuitive to what most parents would expect from regular-functioning children, because students would be tired after being at school all day. Parents discussed seeing this lack of interest get worse as the summer progressed. Data on the impact of summer break on emotions was not found in the review of the literature, so this is a new contribution to the body of literature. A lack of break from parents and lack of structure both contributed to the child’s negative emotions according to parents in interviews.

4.1.5 Child’s Lack of Structure and Break from Parents

The child’s lack of structure and routine was the only code not divided into sub-codes that all ten parents discussed. This is not surprising, as children with autism thrive on structure, and strategies for teaching children with autism include a wide variety of ways to structure that day and the surroundings. Stokes (2001), lists a feature of autism as the need for structured, consistent, routine, and predictable programming. Parents talk about the lack of structure at home, and also defend their lack of structure by talking about the difficulty with making a home as structured as a child with autism requires. It is not possible to schedule predictable days when

a variety of household chores need to be done, that in themselves may not be predictable nor consistent, and parents may not work predictable schedules. As discussed above, the child's lack of structure has an impact on both the child's emotions and the child's maladaptive behaviour, which both have an impact on parent emotions.

Parents discussed their children's lack of break from them in the summer. Unlike other children, children with severe autism are often unable to go out and play with others on their own. Also, due to their other symptoms, such as maladaptive behaviours, it is often difficult to find a reliable care provider or program for them to become involved with. The child's lack of break contributes to the child's emotions, which further influences the child's maladaptive behaviour and the parent's emotions.

4.1.6 Parent's Lack of Structure and Support or Break

Parents also discussed a lack of structure and routine, but unlike the day-to-day structure required by students, it is more like long-term structure that parents need. They can't get into any sort of routine or structure because their relief is not structured or reliable. They feel like they have to beg for workers, or they have workers cancel on them. They have the stress of taking time off work when workers call in sick. A program that gives students the daily structure they require would also give parents the long-term structure they need.

Parents discussed a lack of support or break for themselves. This is the code that directly links to the solutions given by parents. Having support in the form of a program that provides relief, structure, and quality, and that is fully funded, has the potential to be a solution to all of the negative impacts of summer break on both students with severe autism and their families. The literature also found that increased support led to decreased stress in mothers (Ekas, Lickenbrock & Whitman, 2010; Bromley, Hare, Davison & Emerson, 2011).

4.1.7 Financial Issues

Financial issues are a straightforward result of summer break for parents of students with autism, who require relief or care for their children while they work. Although they have the potential to get funding, the funding is difficult for parents to apply for, and it may not cover the relief

required. In addition, even if funding is acquired, workers are often unwilling to work with severely autistic students for the rate they are funded for because working with children with lower severity or needs often pays the same. When there are free programs, parents may not be able to transport their child due to financial issues, such as not having a car or living too far from a half-day program to make the gas money and time worth it. Although parents in this study did not discuss financial issues leading to stress, Falk, Norris & Quinn (2014) found that socioeconomic support was linked to parent mental health.

4.2 Solutions and Recommendations

Research has found that support, especially quality support in the form of care for the person with autism, reduces parent stress. Both Perry (2004) and Bluth, Roberson, Billen, and Sams (2013) argued that social supports are the main support for children with developmental disabilities, including autism. When discussing informal social supports, Bluth et al. (2013) believe that the reason social networks such as extended family and friends fail to consistently provide support is because of the socially unacceptable nature of some of the characteristics of autism. This would put even more weight on formal social supports. Formal social supports include professional or paraprofessional interventions, including educational programs and respite care (Perry, 2004). Parents not only addressed the impact of summer break from school on themselves and their children, but they also gave some solutions to the problems in the interviews in this research. The solutions can be coded into four areas around formal social support: programs that offer relief, programs that offer structure, quality programs and workers, and funding for these programs. Parents feel that these four items in a summer program for their children would reduce the impact of summer on themselves and their own stress, as well as on their children. These recommendations address the primary impacts and in turn address parent stress. Relief programs address the lack of break. Structured programs address the lack of structure. Quality programs and workers address the impact on the child's skills. Funding for programs addresses the parent's financial difficulties.

Recommendations based on this research would be that programs that exist for students with autism would include students with severe autism, or new programs would be created for these students based on the four areas discussed by parents. In addition, the students' goals in the

programs, as well as the IEP goals during the school year, should be appropriately written so that the student does not score too low on an excessively difficult goal. This could reduce the stress of the parents of students with severe autism.

4.3 Application of Models of Disability

When models of disability were applied to the review of the literature on the impact of having a child with autism on parents, there were two distinct forms of social construction recognized by parents, a lack of understanding and acceptance and a lack of support and services. There are also aspects of autism that are recognized as based on impairment. Thomas (2004) calls the lack of understanding and acceptance an internal barrier, or a barrier to being affecting the disabled person's psycho-emotional wellness, and the lack of support and services an external barrier, or a barrier to doing affecting their physical ability to navigate the world. Thomas (2004) includes "impairment effects" in her models. This model would best represent the way parents view autism, because parents also put more weight on social construction than impairment, and talk about the two different types of social construction.

In this research, the models of disability were applied to the qualitative findings of the effects of summer break. Parents discussed the impact of summer break from school on their children with severe autism and themselves. They found a negative impact in the child areas of: a lack of break, a lack of structure, skills, emotions, and behaviour. They also found a negative impact in the parent areas of: lack of break, lack of structure, financial, emotions, and siblings. As these areas all address the social impacts of summer on children with autism because that was the nature of the study, it is the relationships between these impacts and the needs and solutions given by parents to these impacts that really show the model of disability subscribed to by these parents, either intentionally or unintentionally.

Parents made links between the impacts of summer break on themselves and their children during the interviews. They discussed how child behaviour was impacted by child emotions and child lack of structure. They discussed how child emotions were impacted by child lack of break and child lack of structure. They discussed the varied areas that impacted their own parent emotions: their lack of break, their lack of structure, their child's skills, their child's emotions, and their child's behaviour. It is the relationship or links between these areas that parents give

that demonstrates their position on models of disability when it comes to their children.

The most notable link is between child behaviour and the other areas. Summer break has an impact on child behaviour, and parents recognize that the problem is not the child behaviour in and of itself, but that the problem comes from the areas that are linked to child behaviour: child lack of structure and child emotions (which in turn are caused by child lack of structure and child lack of break). Also, parents did not express a need for their child to just stop having behaviours. They expressed a need to resolve the child's lack of structure and child's lack of break that led to the increase of behaviours. They suggested not only relief programs during the summer, but structured relief programs for their children. This demonstrates that these parents follow a social model of disability, because it is not their child's impairment that causes difficulty, but society's lack of support for their child.

The relationship between child emotions and lack of break and lack of structure, as well as the relationship between parent emotions and their lack of break, their lack of structure, their child's skills, their child's emotions, and their child's behaviour, also demonstrates these parent's view of a social model of disability. The children are not sad, stressed, restless, frustrated, and uninterested because they have autism. They have these emotions because of summer break and the lack of break and structure it provides. The parents are not sad, stressed, crazy, impatient, held captive, and tired simply because their children have autism. They express that these emotions come from the summer break and from other areas that are impacted by summer break. Like child behaviour, child emotions can be helped with relief programs that offer structure. Parent emotions can be helped by these structured summer relief programs when they offer quality programs and workers.

The way parents talk about the impact of summer break on themselves and their children with severe autism, drawing links between areas to show that it is the summer break that impacts their child's behaviours and emotions, demonstrates that they follow a very social model of disability. Parents reinforce this when they suggest social supports as solutions to their needs, because they put the onus on society to change, not their children. The stress models previously discussed all included some form of stressor (eg. child characteristic), some form of support (eg. formal support relief), and some form of resource (eg. coping strategies) that led to the outcomes. In the

interviews in this research, parents not only found an impact on relief, as expected, but also an impact on the stressor of the child characteristics of behaviour and skills. The parent recommendations to alleviate their stress outcomes were to increase formal supports, not work on their personal resources. Not one of the parents named psychological help or coping strategies as a solution.

Some parents also discussed their views on disability in the interviews, especially in light of a news article released during the data collection of this research. The article by Bennett-Smith (2013) was about a letter that a family of a child with autism in Oshawa received that went viral over social media. The letter was an angry letter from a neighbour of the family who did not want the child with autism in the neighbourhood. She did not feel that the child should be allowed outside to make noise and scare her “normal children”, and she even suggested euthanasia as a solution. One parent alluded to an event that was discussed in interviews that was closer to home. During the summer of data collection, a local child with autism left a vehicle on the side of a highway and was struck and killed by an oncoming vehicle (Sudbury Northern Life, 2013). The child was known by some of the children in the research group as well as by the researcher. Other parents simply talked about their own negative experiences with their children in public.

Kate said that the writer of the letter in the Bennett-Smith article was:

a perfect example of someone that doesn't understand at all, and I think that people should be more educated on autism because autism, they're very intelligent children. They're not, you know, bad. You know, they're not out there to drive you crazy. They're out there in a different way, they have different ways of showing their emotions and their, you know, and I think that... there should be more education on that like more out there, uh, in the media and, I mean there is some out there in the media, but it's all about trying to find a cure and what it is. I think there should be more of, OK, expect this, you know? Expect that. You know. Expect a child to run out into the middle of the road.

Christie also commented on the writer of the letter, saying, “that got me so mad. Like I read that, and that wasn't even to me and I was so angry, like. And, uh, you know, the only thing the kid

does is make noise.” She says at a different time, “you can't just go and you know euthanize a child because they have autism and they're screaming or they're saying something... You have to find a way that works with them, you know? And, uh, people got to start being a little more, like, um, to tolerate it a little better.”

Both Kate and Christie focus on the things that society should change, not ways that the child with autism or their family should change. Society has to have more awareness and tolerance. When Kate says that the media talks about a cure, but should be talking about what to expect so that people can be more understanding, she is taking a social view of disability instead of a medical view because she feels that the problems people with autism face can be better served by teaching the public than finding a cure.

Kate, Christie, and Jhadxia experienced bad experiences with their children in public. Kate talks about when her child has meltdowns in stores:

Um, well when you're in a store, you know, Walmart or wherever, anywhere really, you know, grocery store um, you have certain people that don't understand, right? So they'll give you like a look, like a disgusted look, you know, like why aren't you controlling your... you know what I mean? Because of his behaviour, right? It bothers me because it's almost like bullying. Not bullying, almost like bullying. You know. It's like, they're disgusted with you because your child is doing that, you know? It's bad enough you have to deal with what he's doing and then have someone look at you like disgusted you know? It just makes me feel bad, you know, about myself and him and I don't want to embarrass him and that's my biggest thing.

Christie agrees that “when they have meltdowns people just think right away that they are being bad or they are being spoiled because they want something and they are not getting it and it's not that.” She talks about a specific issue at her co-op housing. Her child is echolalic and often repeats inappropriate language. A man in her unit confronted her about it angrily and then the manager wrote her a formal letter saying that the screaming is scaring others, asking the mother to “take care of this problem now.” Christie respond to these people in her interview: “If you're not going to want to be part of a community and maybe help somebody, or you know, help spread awareness, like, just don't even bother hating.” Jhadxia talked about the stares and

comments she got when her child was having a meltdown on the city bus. Jhadxia was not mad at her daughter, but felt bad for her because “it wasn't her fault.”

Kate, Christie, and Jhadxia are following a social model of disability when they discuss their children's treatment by the public. They do not feel that the fault lies with their children, but with society, and it is society that needs to change. Kate calls it bullying, Christie calls it hating, and Jhadxia is very clear to say that it was not her child's fault.

Finally, both Nan and Christie were unable to send their children to autism programs because of their children's behaviours. As Nan said, “there's nothing for him for the summer. And that shouldn't be happening because kids like that need more. Like, why wouldn't there be programs for those special kids that are like that? They have programs for other kids. They should have programs for those special kids.”

Nan and Christie also view their children with autism through the lens of a social model of disability, except unlike above where the problem is a lack of understanding of people with autism, they have a problem with the lack of services for people with autism.

Like the findings from the review of the literature, parents in this study also have a very social based model of disability. They talk about a lack of understanding, like Thomas' (2004) “barrier to being” or Patterson and Hughes' (1999) “passive social disability”, as well as a lack of support, like Thomas' “barrier to doing” or Patterson and Hughes “active social disability”. They also still include “impairment effects” in their models. This impairment effect is demonstrated when Kate said, “It's bad enough you have to deal with what he's doing and then have someone look at you like disgusted.” Christie explains the feeling that these parents have about their children well when she says, “I would never change my kids for the world. Never. But, you know, I'd probably try to change the world for them.”

4.4 Limitations and Future Research

Limitations in this study included the small sample size, the formal testing methods, the timing of the PSI assessments, the potential for type two error looking at such a vast amount of data, and the lack of objectivity and bias of a researcher who works with some of the participants.

The sample size of 10 participants was chosen because students with severe autism are rare. Small sample sizes run the risk of type two error, potentially failing to detect an effect (failing to reject the null hypothesis). A larger sample size might have shown significant changes in the VABS and in more areas of the PSI. The decision was made to study a small number of students in depth, while still being able to accomplish all of the tests within narrow periods of time. One of the difficulties with previous research was that participants were tested weeks before the end of the school year, including learning time during the break. The goal here was to accomplish all testing within only a couple weeks of the beginning and end of summer break. Future research should be done using a larger group of participants for the quantitative assessments, although this would require multiple researchers to accomplish all of the goals in the time requirement and a wider geographical area to gather more willing participants.

The testing methods used in this research included both formal tests and testing of individual student goals from their IEPs. The difficulty with the formal tests is that students with severe autism often progress at a level that does not register on formal tests over short periods of time. This does not mean that they don't progress, but progress happens very slowly. The VABS consists of just over 400 task statements that the parent respondent has to reply usually, sometimes/partially, or never to. If the individual student's goal is not one of the 400 task statement, then the progress in that goal will not register. Even if the student's goal is one of the task statements in the VABS, for example, says correct age when asked, if the student goes from saying their name 65% of the time to 40% of the time, they may both be considered sometimes by the responding parent and not register on the assessment, even though it is considered a change in their IEP goal. The solution to this problem in this study in the area of academics was to use the student's individual goals from their IEP, because these were very specific goals that were to be worked on during the baseline period. Not only can the task be created around the student's individual needs, but the criteria used to assess the task can be individualized. Where a typical task in a test might be to know ten letters, an IEP goal might be to know two letters, or it might be to know two letters with partial verbal prompts. Using individual IEP goals would be more difficult to do when testing social skills, life skills, communication, and other behaviours because the skills may not be observable over the short period of time the researcher has for assessment, like academic skills are. For example, if the researcher has ten minutes to test behaviour, and the IEP goal is to reduce hitting to once a day, whether hitting occurs during the

ten minutes may not be representative of the child's current behaviour. Because of this, it would take more time to assess adaptive skills and behaviour using individual IEP goals, and this would require more researchers or greater teacher collaboration to complete assessment in the narrow testing periods. Teacher collaborators would require training on assessment for research. Based on the difficulty teachers had with their minimal involvement in this study, it would be difficult to find teachers willing to put in the extra time to participate in data collection. It could be possible to use teacher reports or tracking even though teacher all record data in slightly different ways, but inter-rater reliability would be a concern when the student changes classes over the summer, and the second teacher may decide to work on different academic goals and not test the goals from the previous year. In the future, research in other areas using student IEP goals is desirable, but this would require multiple researchers for data-collection.

Another limitation was the timing of the meetings. The school PSI rating scale was done two months before the end of the school year, but the summer PSI rating scale took place at the beginning of the summer. Parents may have been less stressed because summer just started or more stressed because of worry about the summer ahead. Also, both summer programs were running at this time, which could not be foreseen by the researcher. Ideally, the PSI would have been done in the middle of the summer, but since VABS rating scale had to be done at the end of the school year and the end of the summer, this would have required a fifth parent meeting. Willing participants were difficult enough to find without having a meeting in the middle of the summer, and the researcher was concerned that it was expecting too much of families.

There is also a potential for type two error when looking at such a vast amount of data. There were two formal assessments completed multiple times with numerous subdomains, many points of data in the demographic information, and two forms of scores (weighted and unweighted) used for the ABLIS IEP goals. Performing statistical analysis on so many points has the potential to detect an effect that may not be present. The triangulation of quantitative data with the qualitative data in the interviews would be helpful in pointing out potential areas of both type one and type two error when the two types of data do not correlate.

The final limitation, the lack of objectivity and bias of a researcher who works with some of the participants, has been addressed in the Bias section of this document. The benefits of having a

researcher who has some understanding of the abilities of the participants outweigh the risk of bias. Bias was reduced using another interviewer for participants known to the researcher, avoiding prompting during assessment, and taking notes about the process during interviews. Bias during data analysis was reduced by having participants member-check the final codes, using tools such as “include synonym” in the NVivo software to code interviews, and by making notes about the process during the coding of the interviews.

4.5 Conclusion

This study expanded on the findings of a negative impact of summer break on reading skills of children with autism in the literature by adding a negative impact on overall academic skills of children with severe autism based on IEP goal assessment and parent interviews. This study expanded on findings of over two weeks of recoupment time after the break for students with special needs by adding research specifically on children with severe autism. An increase in maladaptive behaviours and a decrease in social skills of children with severe autism over the summer in the literature was supported by parent interviews in this study. Contributions to the literature also include an increase in negative child emotions, primarily disinterest, in children with severe autism over the summer. Parents reported that both they and their children experienced a lack of break and structure during the summer.

The links between child adaptive skills and parent stress as well as between child behaviour and parent stress in the literature was supported in this study. Child emotions were also linked to parent emotions in this study. Parent lack of break and structure were linked to parent stress, and the child’s lack of break and structure were linked to parent stress by influencing the child’s emotions and behaviour. Finances were discussed by parents, but unexpectedly were not linked to parent stress in the interviews.

Parents suggested relief programs that were structured with quality workers and funding to prevent this lack of break and structure as well as the impact on the child’s skills and the financial burden on parents. Parents in this study saw their children's disabilities as primarily social, requiring interventions and supports from society, while also acknowledging impairment effects.

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Appendices

Appendix A: Acronyms

ABLIS – Assessment of Basic Language and Learning Skills

ADOS - Autism Diagnostic Rating Scale

ANOVA – Analysis of Variance

APA – American Psychiatric Association

ASD – Autism Spectrum Disorder

CARS – Childhood Autism Rating Scale

DSM – Diagnostic and Statistical Manual

DTT – Discrete Trial Training

IEP – Individual Education Plan

PDD – Pervasive Developmental Disorder

PDD-NOS – Pervasive Developmental Disorder – Not Otherwise Specified

PSI – Parenting Stress Index

SES – Socio-economic Status

VABS – Vineland Adaptive Behaviour Scale

Appendix B: Summary of Summer Regression of Students with Special Needs

| Author | Title | Journal | Year | Disability | Assessment | Groups | Samples | Direction |
|------------------------------|--|--|------|--|---|--|--|---|
| Allen | Regression and Recoupment of Behaviours of Severely Multiple Handicapped Children: An Evaluation of An ESY Program | Doctoral Dissertation | 1984 | Severely Multiple Handicapped | direct observation | ESY students compared to non-ESY students | 45 ESY 13 no program | regression in behaviour |
| Allinder and Eicher | Bouncing Back: Regression and Recoupment Among Students with Mild Disabilities Following Summer Break | Special Services in the School | 1994 | Mild Disabilities | CBM – from Math in Stride and Houghton Mifflin Reading | Compared to recoupment | 75 | reading and math regression |
| Allinder and Fuchs | The Effects of Summer Break on Math Skills of Learning Disabled and Low-Achieving Students | B.C. Journal of Special Education | 1991 | Learning Disability | Math Computation Test | compared low achieving to learning disabled students | 34 low 10 disabled | no math regression |
| Allinder and Fuchs | Alternative Ways of Analyzing Effects of a Short School Break on Students With and Without Disabilities | School Psychology Quarterly | 1994 | Mild Disabilities | CBM | Compared to students without disabilities | 84 mild disability 44 no disability | no math regression |
| Beatty | Maintaining the Reading Levels of Learning Disabled Students During the Summer | Doctoral Dissertation | 1985 | Learning Disability | Woodcock Reading Mastery Test | compare LD summer program to LD no program and non-LD no program | 28 LD program 30 LD no-program | no regression in reading |
| Cornelius and Semmel | Effects of Summer Instruction on Reading Achievement Regression of Learning Disabled Students | Journal of Learning Disabilities | 1982 | Learning Disability | Slosson Oral Reading Test (SORT) | Entire summer off compared to two summer programs | 30 LD no program 30 LD program | reading regression |
| Cortex and Hotard | Loss of Achievement Gains Over Summer Vacation | Research Report | 1984 | Remedial | SRA/Computer Assisted Instruction | Compared to baseline | 396 | regression in math, not in reading |
| DeVito and Long | The Effects of Spring-Spring Vs. Fall-Spring Testing Upon the Evaluation of Compensatory Education Programs | Paper Presentation | 1977 | Compensatory Education | California Achievement Test (CAT) | Spring-spring compared to fall-spring for same students | 238 | reading regression |
| Fox | Reading Comprehension and the Summer Setback Phenomenon between Grade 4 and 5 | Doctoral Dissertation | 2008 | Low-income students with special ed variable | New York English Language Arts Assessment | Special education included as variable in study | 445 | reading regression, but similar to others |
| Franklin | The Effect of an Eight-Week Summer School Program on Reading Performance of Severely Emotionally-Disturbed Students | Doctoral Dissertation | 1987 | Emotionally Disturbed | Peabody Individual Achievement Test, Peabody Picture Vocabulary Test | compare students in summer school to control | 10 no program 45 program | no regression in reading |
| Handleman and Harris | Can Summer Vacation Be Detrimental to Learning? An Empirical Look | The Exceptional Child | 1984 | Autism | Peabody Cards | two sets of labels for each student, with/without break | 4 | regression in word recognition |
| Menousek | An Analysis of the Factors Affecting Regression and Recoupment of Skills of Special Education Students Following Summer Vacation | Doctoral Dissertation | 1983 | Special Education "severe/profound to trainable range" | IEP and Adaptive Behaviour Scale | Compared to baseline | 67 | regression in self help and behaviour |
| Shaw | Retention of Selected Reading and Arithmetic Skills by Learning Disabled Pupils and Non-Disabled Pupils over Summer Vacation | Master's Thesis | 1982 | Learning Disability | Wide Range Achievement Test (WRAT) Level 1 Reading and Mathematics subtests | Disabled students and non-disabled students | 128 non disabled 108 LD resource 58 LD special class | reading and arithmetic regression |
| Waugh, Fredrick, and Alberto | Using Simultaneous Prompting to Teach Sounds and Blending Skills to Students with Moderate Intellectual Disabilities | Research in Developmental Disabilities | 2009 | moderate intellectual disabilities | sight word cards, letter sound cards, and word cards | Single-subject | 3 | regression to no regression in sight word recognition |
| Wilkins | Parent Training as a Service Delivery Model for 12 Month Programming | Paper Presentation | 1983 | Moderately to Severely Handicapped | varied... VULPE etc. | Students with parent training are compared to students without | 15 parent trained 25 no program | regression in various goals |

Appendix C: Recruitment Letters and Consent Form



Dear Parent:

I am a PhD Candidate at Laurentian University in the Interdisciplinary Human Studies programme. I am studying the impact of summer break from school on children with severe autism and their parents, including the impact on learning and parent stress. The study is intended to inform decisions about summer programs for students with autism. I would like to invite your family to participate in this research.

The study will involve filling in two rating scales, two to four times each, and participating in three interviews. These rating scales and interviews will take place during four meetings spread over eight months that are expected to last from 30 to 90 minutes each. Your child(ren) may be present during the meetings, and the meetings will be planned for a mutually convenient time. The interviews will be private and confidential. The interviews will be recorded. You will not be required to answer any questions you do not wish to. Your child will also be assessed on math and reading Individual Education Plan (IEP) goals four times over the eight months at their school. This assessment is expected to take approximately 10 minutes each time.

Your participation in this study is strictly voluntary and you have the right to withdraw at any time without penalty. I am a special education teacher with the Rainbow District School Board, so any participating families from my class will be interviewed by an alternate interviewer. Participants will not receive preferential treatment, and there will be no consequences for non-participation. If you wish to participate or have any questions or concerns about the study or about being a subject, you can call me at 705-674-1221 or return this letter to the school with your phone number below. Participants may contact a research ethics officer not attached to the research team regarding possible ethical issues or complaints about the research itself at the Laurentian University Research Office at 705-674-1151 ex. 2436, toll free at 1-800-461-4030 or at ethics@laurentian.ca. Your identity will not be revealed at any time. Thank you so much for taking the time to consider participation.

Sincerely,

Jana Duncan, Researcher

Dr. Elizabeth Levin, Supervisor

Parent's Name

Phone Number



To the Principal:

I am a PhD Candidate at Laurentian University in the Interdisciplinary Human Studies programme and a special education teacher with the Rainbow District School Board. I am studying the impact of summer break from school on children with severe autism and their parents, including the impact on learning and parent stress. The study is intended to inform decisions about summer programs for students with autism.

I am looking for families of children with severe autism from your school to participate in this study. They must be between the ages of 4 and 12 as of March 1st, 2013, be in school full time, not be in IBI, and be within the range of the ABLLS in reading and math.

The study will involve interviews and rating scales with the parents at home. Brief assessments of ABLLS goals in reading and math from the IEP at four time points throughout the school year will be done with the students at school. Teachers will be asked to provide the child's first two IEP goals from the ABLLS in both reading and math. A space will be required for assessments in a location familiar to the student for the length of time it takes to assess four goals. The estimated time is ten minutes four times over the course of eight months for each student. These assessments will be arranged ahead of time with the teacher at a time convenient for all parties.

Consent by non-verbal or low-verbal children will be acquired by asking parents about ways the student communicates "no" and observing the child for this communication during assessment. High reinforcers will be used during assessment based on suggestions by parents, and students will have a second opportunity to be assessed at a later time for each assessment. Consent from parents to assess the child and access the child's IEP will be acquired before the first school meeting.

Please send the attached recruitment form home to parents of children diagnosed with severe autism from your school. It would be appreciated if someone from the school could communicate the need for participants to parents by telephone as well. If you have any questions or concerns about the study, you can call me at 705-674-1221 or my supervisor, Elizabeth Levin, at 705-675-1151 ex.4242. Thank you so much for taking the time to assist me in my research.

Sincerely,

Jana Duncan, Researcher

Dr. Elizabeth Levin, Supervisor



To the teacher of students with autism:

I am a PhD Candidate at Laurentian University in the Interdisciplinary Human Studies programme and a special education teacher with the Rainbow District School Board. I am studying the impact of summer break from school on children with severe autism and their parents, including the impact on learning and parent stress. The study is intended to inform decisions about summer programs for students with autism.

I am looking for families of children with severe autism from your class to participate in this study. They must be between the ages of 4 and 12 as of March 1st, 2013, be in school full time, not be in IBI, and be within the range of the ABLLS in reading and math.

Brief assessments of ABLLS goals in reading and math from the IEP at four time points throughout the school year will be done with the students at school. Teachers will be asked to provide the child's first two IEP goals from the ABLLS in both reading and math. If specific resources are not provided in the IEP, they will be requested as well. For example, if the IEP goal is to read 10 words, the list of words taught will be requested. If the goals are revised during the term, the new goals will be requested. A space will be required for assessments in a location familiar to the student for the length of time it takes to assess four goals. The estimated time is ten minutes four times over the course of eight months for each student. These assessments will be arranged ahead of time with the teacher at a time convenient for all parties.

Consent by non-verbal or low-verbal children will be acquired by asking parents about ways the student communicates "no" and observing the child for this communication during assessment. High reinforcers will be used during assessment based on suggestions by parents, and students will have a second opportunity to be assessed at a later time for each assessment. Consent from parents to assess the child and access the child's IEP will be acquired before the first school meeting.

Please send the attached recruitment form home to parents of children diagnosed with severe autism from your class. It would be appreciated if someone from the school could communicate the need for participants to parents by telephone as well. If you have any questions or concerns about the study, you can call me at 705-674-1221 or my supervisor, Elizabeth Levin, at 705-675-1151 ex.4242. Thank you so much for taking the time to assist me in my research.

Sincerely,

Jana Duncan, Researcher

Dr. Elizabeth Levin, Supervisor



Study Title: The Impact of Summer Break from School on Children with Severe Autism and their Parents

Investigator: Jana Duncan

I am a PhD Candidate at Laurentian University in the Interdisciplinary Human Studies programme. I am studying the impact of summer break from school on children with severe autism and their parents, including the impact on learning and parent stress. The study is intended to inform decisions about summer programs for students with autism.

The study will involve filling in two rating scales two to four times each and participating in three interviews. These rating scales and interviews will take place during four meetings spread out over eight months that are expected to last from 30 to 90 minutes each. Your child(ren) may be present during the meetings, and the meetings will be planned for a mutually convenient time. The interviews will be private and confidential. The interviews will be recorded. You will not be required to answer any questions you do not wish to. Your child will also be assessed on math and reading Individual Education Plan (IEP) goals four times over the eight months at their school. This assessment is expected to take approximately 10 minutes each time.

Your participation in this study is strictly voluntary and you have the right to withdraw at any time without penalty. I am a special education teacher with the Rainbow District School Board, so any participating families from my class will be interviewed by an alternate interviewer. Participants will not receive preferential treatment, and there will be no consequences for non-participation. Consent by non-verbal or low-verbal children will be acquired by asking parents about ways the student communicates “no” and observing the child for this communication during assessment. High reinforcers will be used during assessment based on suggestions by parents, and students will have a second opportunity to be assessed at a later time for each assessment.

If you have any questions or concerns about the study or about being a subject, you can call me at 705-674-1221 or my supervisor, Elizabeth Levin, at 705-675-1151 ex.4242. Participants may contact a research ethics officer not attached to the research team regarding possible ethical issues or complaints about the research itself at the Laurentian University Research Office at 705-674-1151 ex. 2436, or toll free at 1-800-461-4030, or at ethics@laurentian.ca. Your identity will not be revealed at any time. Thank you so much for taking the time to participate.

Sincerely,

Jana Duncan, Researcher

Dr. Elizabeth Levin, Supervisor

Consent Form

Study Title: The Impact of Summer Break from School on Children with Severe Autism and their Parents

Investigator: Jana Duncan

I agree to participate in this study, and I have received a copy of this consent form. I also give my permission for my child to participate in this study at school.

I give permission for the researcher to access my child's IEP through the school, and to request specific details from the classroom teacher. (For example, if the IEP goal is to read ten words, the researcher will ask the teacher for a list of the words.) This consent form is valid for the purposes of this research for one year or until it is cancelled in writing by the authorizing person (the parent), whichever comes first.

Student's Name

Date of Birth

School

Parent's Name

Address

Parent's Signature

Date

Phone Number

The student's methods of communicating "no":

The student's 5 highest reinforcers, from most reinforcing to least reinforcing:

- 1.
- 2.
- 3.
- 4.
- 5.

Appendix D: Ethics Approval



Laurentian University
Université Laurentienne

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

| TYPE OF APPROVAL / New X / Modifications to project / Time extension | |
|---|---|
| Name of Principal Investigator and school/department | Jana Duncan |
| Title of Project | The Impact of Summer Break from School on Children with Severe Autism and their Parents |
| REB file number | 2013-001-14 |
| Date of original approval of project | March 17, 2013 |
| Date of approval of project modifications or extension (if applicable) | |
| Final/Interim report due on | March 17, 2014 and then annually until complete |
| Conditions placed on project | Final report due on August 31, 2016 |

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate REB form.

In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

Susan James, Acting chair
Laurentian University Research Ethics Board



69 Young Street, Sudbury, Ontario P3E 3G5 | Tel: 705.674.3171 | Toll Free: 1.888.421.2661 | rainbowschools.ca

March 27, 2013

Jana Duncan
17 Lambton Court
Sudbury P3E 3P1

Dear Jana Duncan:

The purpose of this letter is to inform you that your Research Project Proposal entitled "**The Impact of Summer Break from School on Children with Severe Autism and their Parents: An Interdisciplinary Study**" will be approved with a revision.

The Education Research Review Committee felt a letter of introduction to teachers outlining the commitment of time in the study is required. Please revise the parent letter to indicate how many times they will be interviewed (rather than *multiple* times).

The Education Research Council would appreciate receiving a copy of your completed research project so that we might ascertain its impact in our school system.

Sincerely,

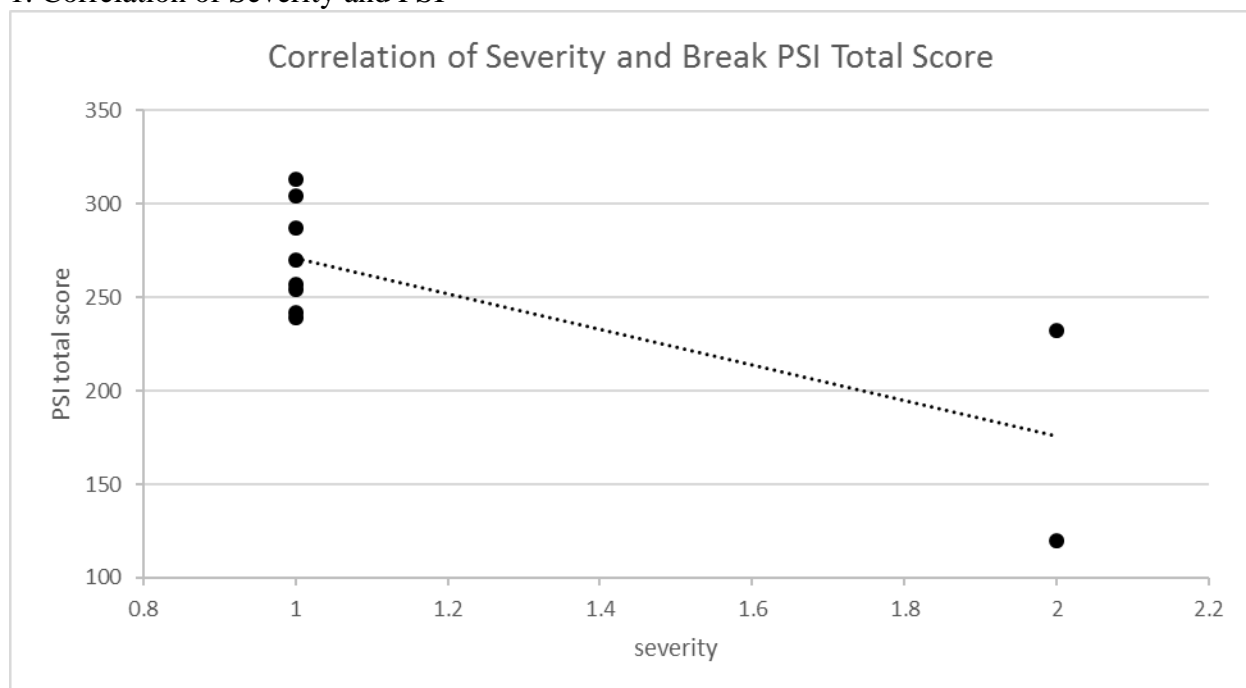
A handwritten signature in dark ink, appearing to read "Sharon Speir", is written over the typed name.

Dr. Sharon Speir
Superintendent of Schools
Rainbow District School Board
speirs@rainbowschools.ca

Encl. (1)

Appendix E: Correlation Graphs

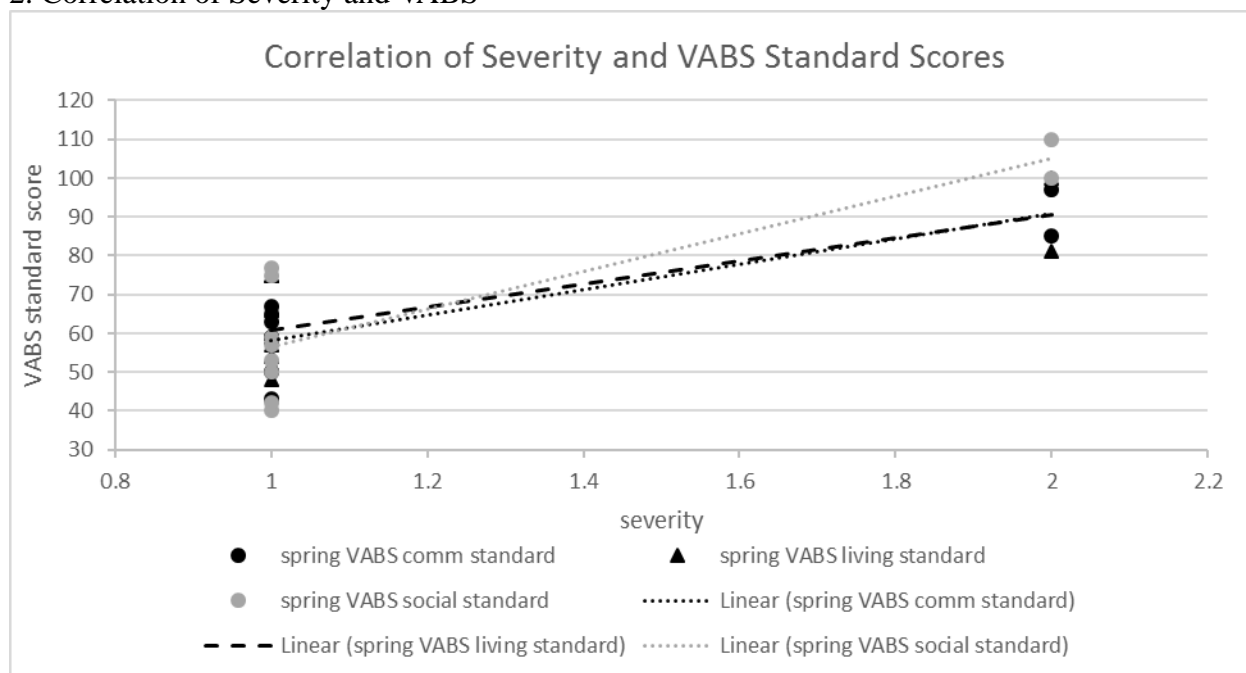
1. Correlation of Severity and PSI



**severity 1=severe diagnosis, 2=moderate diagnosis*

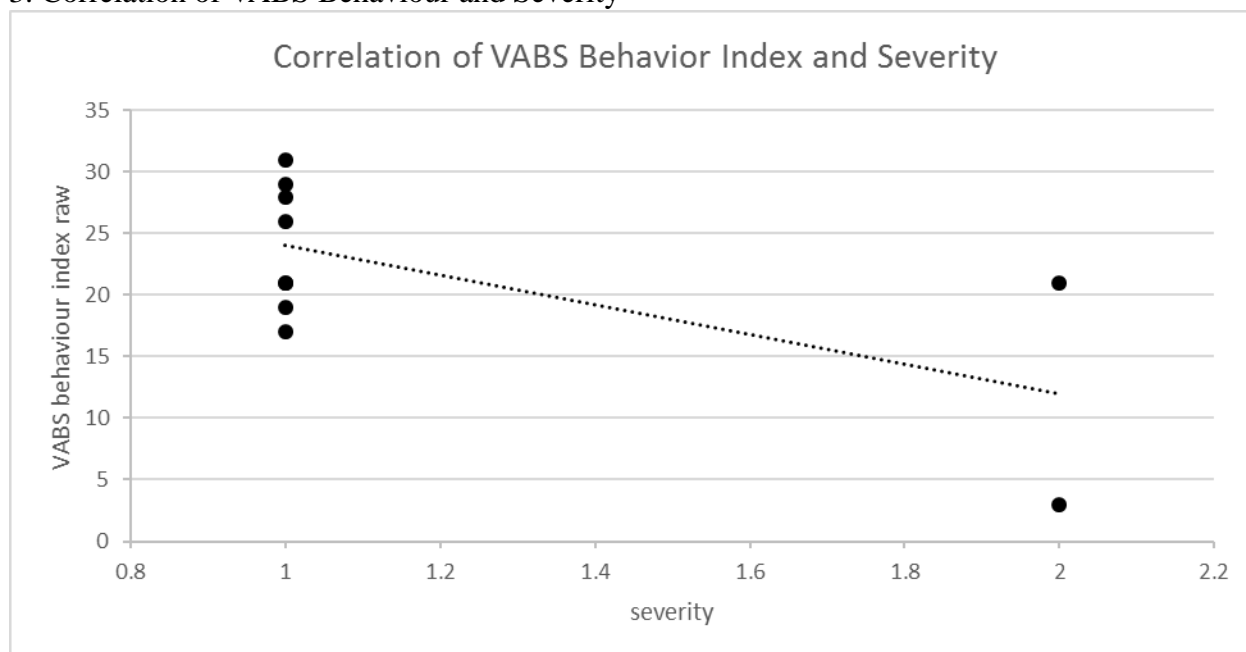
**a higher PSI score represents more stress*

2. Correlation of Severity and VABS



**severity 1=severe diagnosis, 2=moderate diagnosis*

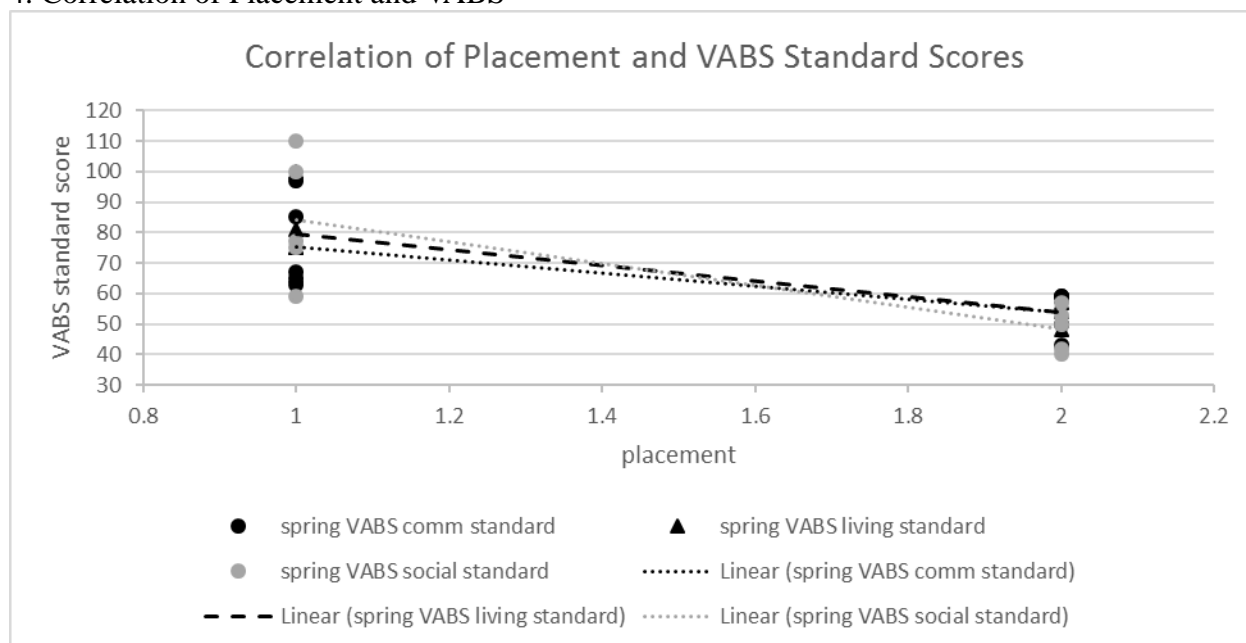
3. Correlation of VABS Behaviour and Severity



**severity 1=severe diagnosis, 2=moderate diagnosis*

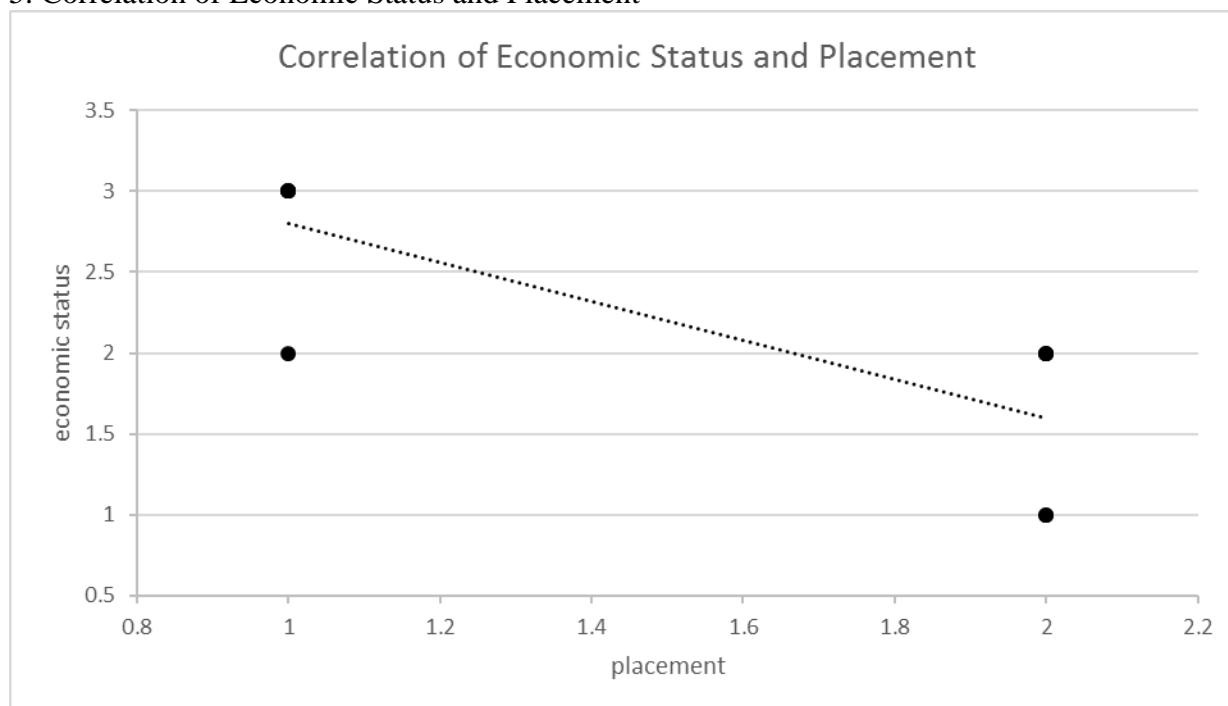
**a higher VABS raw behaviour index represents more maladaptive behaviours*

4. Correlation of Placement and VABS



**placement 1=self-contained class, 2=self-contained school*

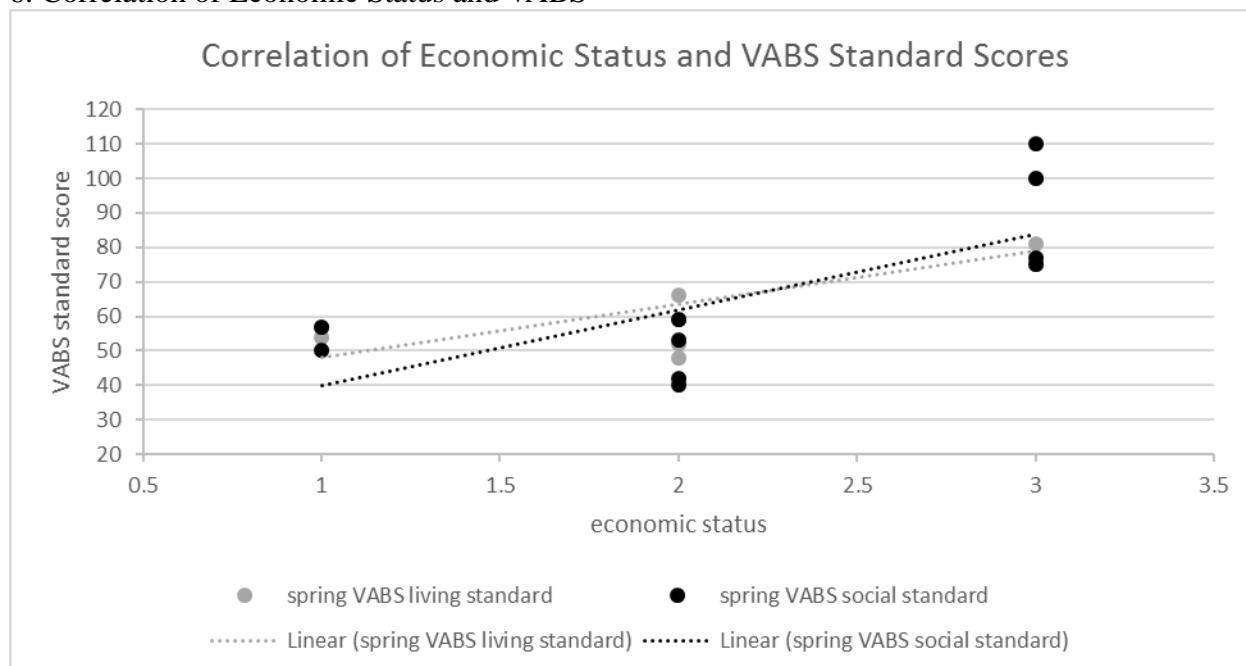
5. Correlation of Economic Status and Placement



**economic status 1=<\$25,000, 2=\$25,000-\$90,000, 3=>\$90,000 family income per year based on parent self-reporting*

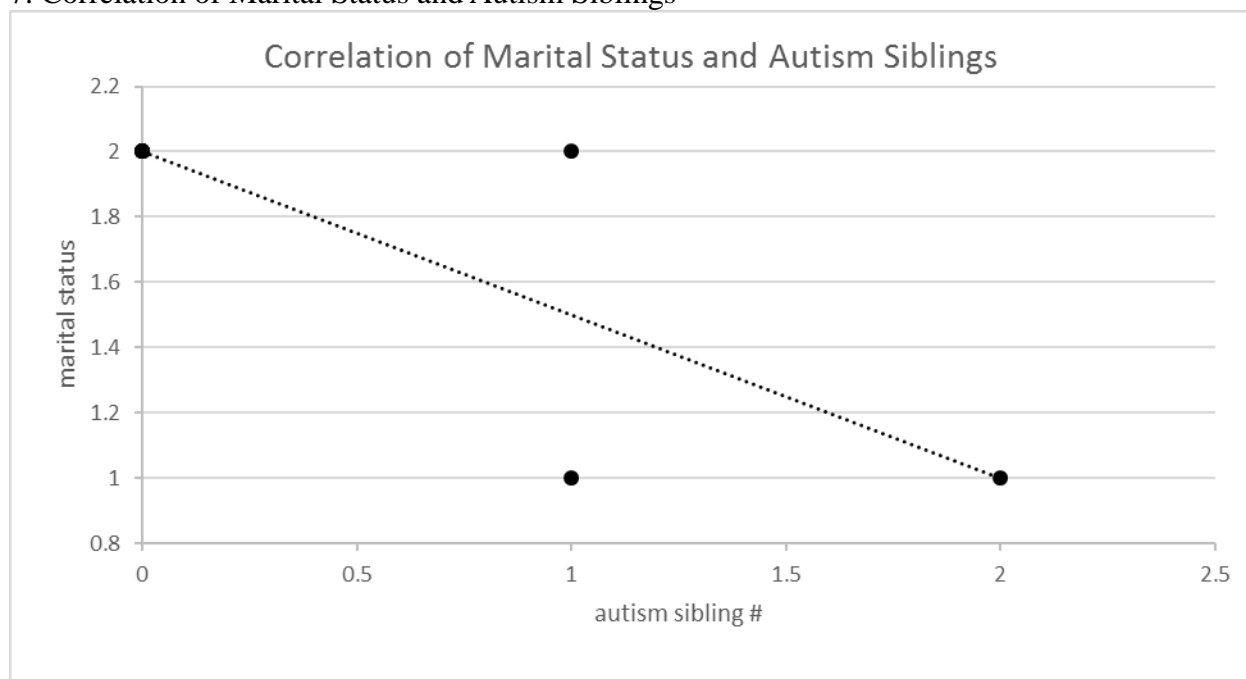
**placement 1=self-contained class, 2=self-contained school*

6. Correlation of Economic Status and VABS



**economic status 1=<\$25,000, 2=\$25,000-\$90,000, 3=>\$90,000 family income per year based on parent self-reporting*

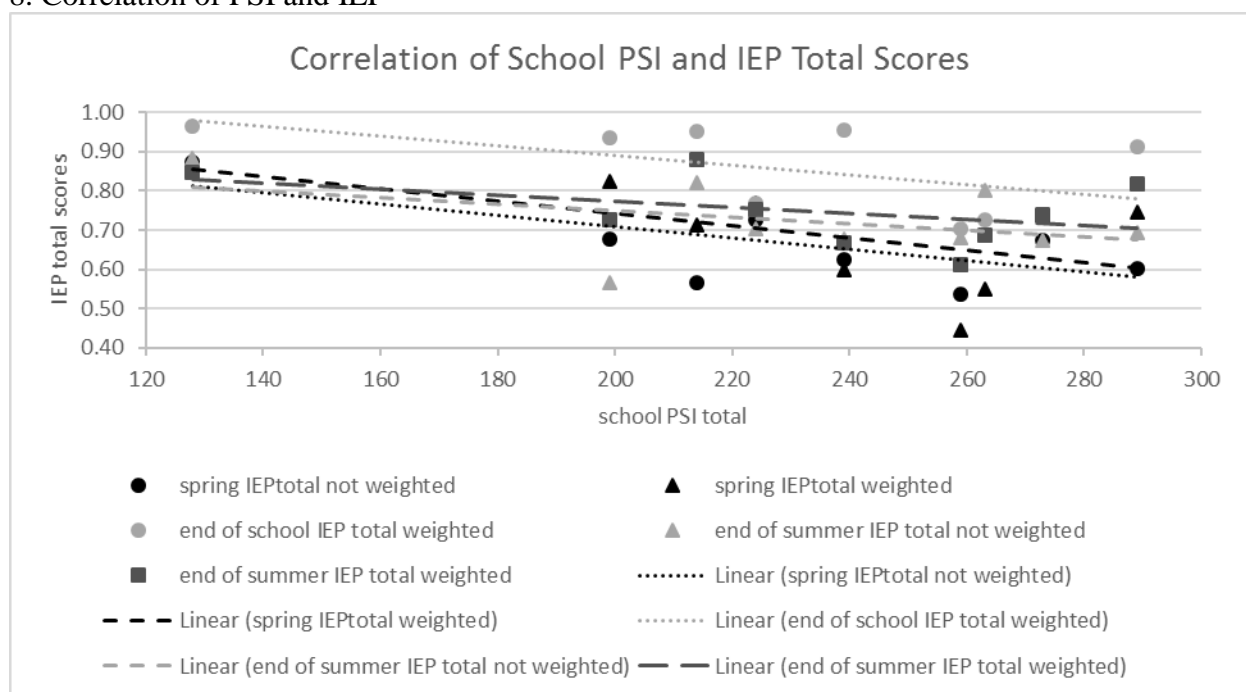
7. Correlation of Marital Status and Autism Siblings



**economic status 1=<\$25,000, 2=\$25,000-\$90,000, 3=>\$90,000 family income per year based on parent self-reporting*

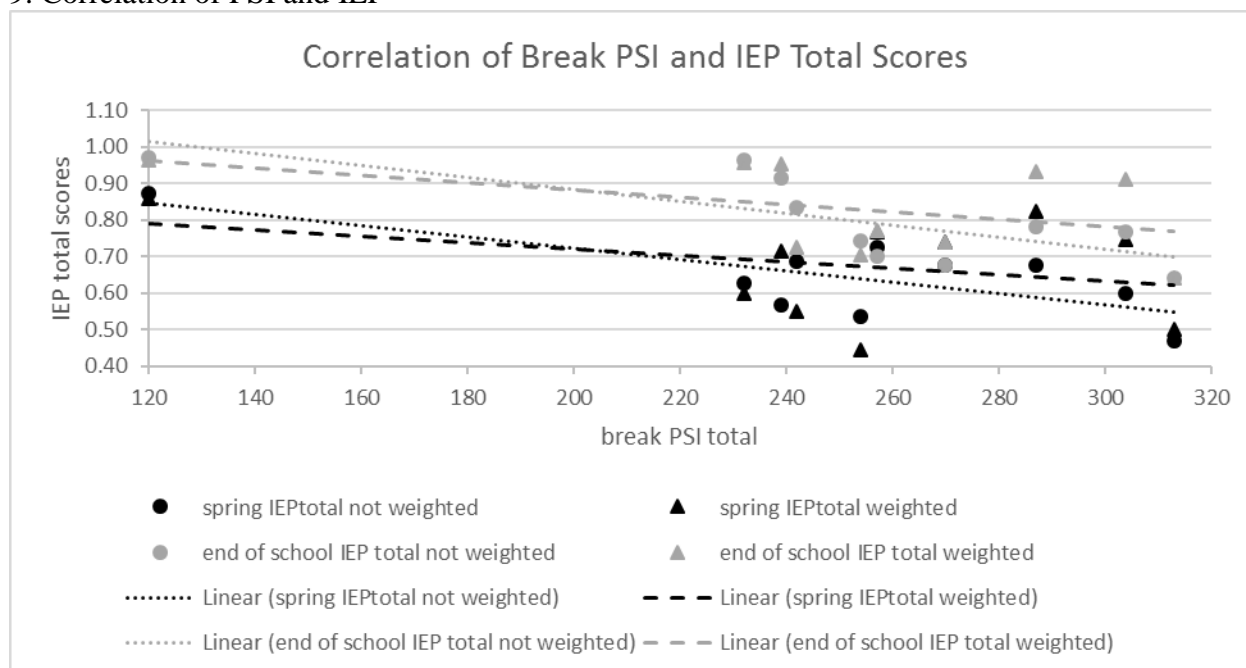
**autism sibling # is the number of siblings with autism the participant child has*

8. Correlation of PSI and IEP



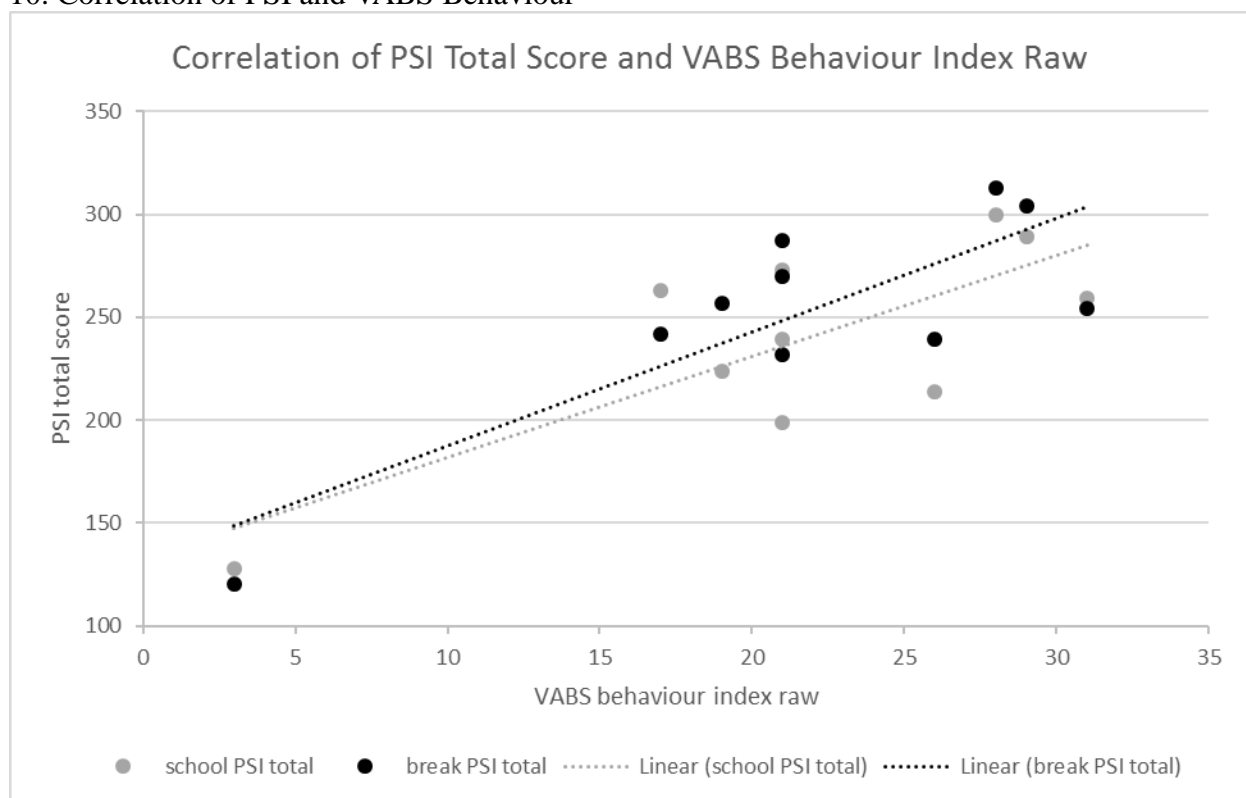
**a higher PSI score represents more stress*

9. Correlation of PSI and IEP



**a higher PSI score represents more stress*

10. Correlation of PSI and VABS Behaviour



**a higher PSI score represents more stress*

**a higher VABS raw behaviour index represents more maladaptive behaviours*